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# Perinatal Palliative Care: Assessment of Practice Barriers, Clinician Perspectives and Confidence

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# PERINATAL PALLIATIVE CARE: ASSESSMENT OF PRACTICE BARRIERS, CLINICIAN PERSPECTIVES AND CONFIDENCE

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of
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Abstract

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Perinatal palliative care (PPC) is an emerging model of care that provides supportive services to families anticipating fetal or neonatal demise. Clinician reported practice barriers, their perspectives of PPC and confidence in caring for patients requiring PPC are unknown. The aim of this research is to fill a gap in understanding clinician perspectives, perceived practice barriers and reported confidence to providing PPC. A cross sectional survey design using the Perinatal Palliative Care Perceptions and Barriers Scale © was administered using a Web-based tool. Recruitment was completed via email invitation and list serves. Participants included physicians (n = 66) and advance practice nurses (n = 146). T-test and Mann-Whitney U were used to examine differences in perceived practice barriers, clinician perspectives, comfort and confidence in delivering PPC. Hierarchical multiple regression was used to test the hypothesis that clinician perceptions, barriers to PPC, years in clinician practice, referral comfort and personal comfort and

case history explain variation in confidence. Physicians and nurses have fundamentally similar perspectives but report significant differences in perceived practice barriers, their comfort with providing and referring patients to PPC and their confidence in delivering such care. A significant regression equation with an overall $R^2$ of .56 explained variation in confidence. Palliative care involves physicians and nurses making synergistic contributions to the care of families expecting a baby with a life-limiting diagnosis. Clinicians are positioned to collaboratively develop PPC programs and can benefit from interventions aimed at modifying practice environments. Supportive interventions and educational initiatives may increase clinician comfort and confidence with palliative care delivery.

Key Words: Perinatal palliative care; perinatal hospice; clinician confidence; physician confidence; nurse confidence

# Chapter 1

Perinatal palliative care (PPC) is an emerging specialty dedicated to providing health care to fetuses diagnosed prenatally with life-limiting conditions, as well as supportive care to parents and family members (Munson & Leuthner, 2007). The goal of this research was to investigate clinician perspectives, confidence, and perceived barriers to PPC service implementation. This study was built on research conducted during the course of my doctoral preparation. I led a group of national experts in Delphi methodology to develop an instrument to measure clinician perceptions and practice reported barriers to PPC (Appendix A). The instrument was then successfully piloted with several hundred multidisciplinary respondents. Results from the pilot were used to construct this dissertation research which focuses on the perspectives, experiences and challenges of the physicians and advance practice nurses (APNs) who serve bereaved families. Specifically, the following research questions were addressed:

Ha1: PPC practice barriers differ between physicians and APNs

Ha2: There are differences in perceptions as they pertain to PPC between physicians and APNs

Ha3: PPC perceptions, PPC barriers, years in practice, PPC case history, referral comfort, personal comfort, and personal experience with perinatal loss explain clinician overall confidence in their ability to deliver PPC in their setting

The purpose of the study was to understand the beliefs and challenges facing clinicians who are on the front lines of caring for families facing the agonizing dilemma

of dealing with a fetal terminal diagnosis. Understanding the issues will enable clinical educators to develop and deliver programs designed to foster better understanding of the issues involved in PPC. The ultimate goal is to reduce barriers, advance understanding of PPC, and facilitate strong support systems that enable clinicians to provide optimal palliative care services. Optimizing PPC will enable families who elect to continue a pregnancy to its natural end to deal with the varied challenges with caring support and understanding.

A cross-sectional nationwide survey was conducted using the Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS). The survey was administered using a computer-mediated, Web-based tool called Qualtrics. Purposive, convenience sampling of licensed clinicians was obtained via email invitations sent out by the principal investigator and select clinician colleagues across the United States. Recruitment was facilitated through flyer distribution at a national nursing convention and invitations posted on two perinatal list serves. Sixty-six physicians and 146 APNs completed the survey as well as 90 clinicians from other disciplines. Data analysis included t-tests to examine differences in perspectives and perceived practice barriers between physicians and advance practice nurses. In order to examine clinician-specific issues, Mann Whiney *U* was calculated on individual items in the perception and barriers scales. Hierarchal multiple regression was utilized to explain clinician self-reported confidence using several variables.

Results of this study indicate clinicians report many barriers to providing PPC, with physicians and APNS reflecting significant differences in the barriers they experience. However, clinicians share ethical perspectives regarding PPC and are well positioned to collaboratively develop PPC programs. Physicians and nurses report significant differences in their comfort with providing and referring patients to PPC and their confidence in delivering such care. A significant regression equation with an overall $R^2$ of .56 explained variation in confidence.

## Introduction of the Articles

My doctoral journey began several years before enrolling at The University of Texas at Tyler. Several colleagues encouraged me to consider investigating palliative care. The patients I have worked with have also taught me a great deal and my experiences with them help guide my work. In the spring of 2010 faculty members encouraged me to apply for a grant to examine clinician attitudes and reported practice barriers to PPC. Funding for the grant was awarded in the summer of 2010 and made it possible to conduct research while being under the mentorship of faculty members. Two manuscripts have emerged as a direct result of my tenure at University of Texas at Tyler. The first was a systematic review of the literature (Appendix B), written as a part of my coursework and the second is the result of the research conducted in the summer and fall of 2010 (Appendix C). I also recently had the opportunity to co-author a manuscript with physician and nurse colleagues in California who experienced challenges in the neonatal intensive care unit due to parental demands for protracted neonatal intensive care which

caused extensive suffering to the infant and precipitated feelings of distress in clinicians.

The team in California asked me to provide insights into perinatal palliative care and its potential to relieve providers and parents of undue suffering. The first manuscript, entitled *Systematic review of the literature: Parental outcomes after diagnosis of a fetal anomaly* (Wool, 2011), written for my Quantitative Research Designs & Methods course, provided data on neonatal mortality in the US and discussed the ability of technology to increasingly detect fetal abnormalities in the early pregnancy. Sadly, the detection of anomalies often does not include a course of treatment and parents are compelled to make difficult choices based on limited options. Both giving birth to a child with a life limiting condition or termination of pregnancy can be emotionally traumatic life events. Women speak of unbearable stress during the decision-making process, the difficulty in processing through the stigma of termination, and the difficulties inherent in delivering a disabled infant. Participants describe guilt, anger, post-traumatic stress, and profound grief following medical termination. With time, however, the negative impact of the termination seems to pass.

Alternatively, women who choose to carry the pregnancy to term may benefit from PPC. To date, three exploratory descriptive studies examined programs designed to offer supportive services. Calhoun and colleagues (2003) found parents to whom comprehensive, multidisciplinary, individualized and informed counsel was given chose PPC 85% of the time. Parental response to this model of care was reported as overwhelmingly positive. In another exploratory study, forty percent of parents chose to

continue their pregnancy and pursue PPC. Parents provided positive feedback about their decision and the care provided. D'Almeida and associates (2006) engaged 28 families diagnosed with a prenatal congenital anomaly. Seventy-five percent opted to participate in PPC without any notable maternal morbidity and families expressing positive feedback. Women and their families appear to benefit from anticipatory guidance and coordinated and compassionate support services. Information related to potential emotional responses post event should be provided and referrals to counseling services may also be beneficial.

Funding received from Sigma Theta Tau-Hospice Palliative Nurse Foundation in 2010 provided an opportunity to develop and pilot an instrument to measure clinician attitudes and beliefs about PPC and examine practice barriers. A manuscript currently in press with Advances in Neonatal Care (Wool & Northam, 2011) called *The Perinatal Palliative Care Perceptions and Barriers Scale Instrument©: Development and Validation* explains the process of instrument development from initial contact with a panel of perinatal palliative care experts and includes the results of factor analysis. The instrument was found to be a valid and reliable measure of PPC perspectives and perceived barriers for measuring the attitudes of physicians and nurses.

## Modifications made to study based on pilot work

The pilot study included a total of 264 clinicians, 69 of whom were physicians and nurses. Dissertation research built upon the pilot with an aim to garner feedback from more physicians and advance practice nurses with the rationale that these clinicians

interact with families most often. Additionally, the Institute of Medicine recognizes physicians and nurses as core stakeholders in the interdisciplinary team (Field & Behrman, 2003) for children and families in need of palliative care.

Clinician perceptions and perceived practice barriers were measured in this study and the concepts of clinician comfort and confidence with PPC were added. There is an assumption that clinicians have the knowledge and proficiency to assess and manage patients' physical, psychological, and spiritual concerns involved in PPC. However, it is uncertain if perinatal providers are familiar with the tenets of palliative care. Since PPC is a newly emerging specialty, it is unknown if clinicians are comfortable with delivering such care, or if they are confident in their ability to provide appropriate supportive services for this unique patient population. Issues impeding feelings of confidence in providers can create hesitation in participating with palliative care modalities or providing patients with timely and appropriate referrals.

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# Chapter 2 : Clinician Confidence and Comfort in Providing Perinatal Palliative Care

Abstract and manuscript prepared for *Journal of Obstetric, Gynecologic, and Neonatal Nursing*

## Abstract

Objective: This study measured the differences in perceptions of physicians and advance practice nurses, their reported comfort in providing and referring patients to perinatal palliative care (PPC) and their confidence in delivering such care.

Design: A cross sectional survey design using the Perinatal Palliative Care Perceptions and Barriers Scale ©

Setting: A survey was administered using Qualtrics, a Web-based tool. Recruitment was completed via email invitation and list serves.

Participants: Physicians (n = 66), advance practice nurses (n = 146), and other clinicians (n = 90)

Methods T-test and Mann-Whitney U were used to examine differences in clinician perspectives, comfort and confidence in delivering PPC. Hierarchical multiple regression (HMR) was used to test the hypothesis that clinician perceptions, barriers to PPC, years

in clinician practice, referral comfort and personal comfort and case history explain variation in confidence.

Results: Physicians and nurses have fundamentally similar perspectives but report significant differences in their comfort with providing and referring patients to PPC and their confidence in delivering such care. A significant regression equation with an overall $R^2$ of .56 explained variation in confidence.

Conclusion: Palliative care involves physicians and nurses making unique and positively synergistic contributions to the care of families expecting a baby with a life-limiting diagnosis. Clinicians share ethical perspectives regarding PPC and are positioned to collaboratively develop PPC programs. Barriers to PPC delivery exist and clinicians can benefit from interventions aimed at modifying practice environments. Supportive interventions and educational initiatives may increase clinician comfort and confidence with palliative care delivery.

Key Words: Perinatal palliative care; perinatal hospice; clinician confidence; physician confidence; nurse confidence

## Manuscript

There are times when technology outpaces medicine's ability to intervene and provide curative care. For parents expecting a child, clinical information such as a reassuring heartbeat or images of fetal movement through ultrasound are often eagerly anticipated events. Unfortunately, there are increasing instances when providers must deliver unanticipated, bad news to parents because prenatal diagnostic imaging is detecting fetal anomalies in the first and second trimester (Peach & Hopkin, 2007). Families are often unprepared for receiving prognostic information that addresses complicated fetal diagnoses and potentially entails lethal or life-limiting conditions. Predictably, they react with a variety of emotions including profound grief and shock (Statham, Solomou & Chitty, 2000). It is at this juncture that health professionals are uniquely positioned to establish a meaningful healing environment for suffering parents. Clinicians need the confidence to know how to carefully and compassionately disclose information and offer support to families as the loss event unfolds.

In these uncomfortable and challenging situations, clinicians have a critical role and professional obligation to deliver appropriate services to these expectant parents. This service is manifested by guiding parents through a potentially complex decision-making process, providing appropriate informed consent, and delivering competent and compassionate care after their choice is articulated. Clinical providers have often presented two options: 1) carry the pregnancy to term and provide maximal life-extending care to the neonate, or 2) terminate the pregnancy (Feudtner & Munson, 2010). Recently however, the American College of Obstetricians and Gynecologists and the

American Academy of Pediatrics (2011) published recommendations to help direct clinicians in their care for families expecting an impaired baby. These recommendations state "the informed consent process should involve thorough discussion of the risks and benefits for both the fetus and the pregnant woman. The full range of options, including fetal intervention, postnatal therapy, palliative care, or pregnancy termination, should be discussed (p e477)." Perinatal palliative care (PPC) is an emerging specialty dedicated to providing health care to fetuses diagnosed prenatally with life-limiting conditions along with supportive care to parents and family members (Munson & Leuthner, 2007). The PPC model begins at fetal diagnosis and extends into the postpartum period often requiring a multidisciplinary response generally coordinated by an experienced perinatal nurse (Leuthner & Jones, 2007; Ramer-Chrastek & Thygeson, 2005). Clinicians who provide care to families choosing a PPC model offer a variety of interventions such as advance care birth planning, bereavement support, continuity and quick access to care, consistent delivery of information, comfort-maximizing care for the neonate, and provision of meaningful rituals (Capitulo, 2005).

There is an assumption that clinicians have the knowledge and proficiency to assess and manage patients' physical, psychological and spiritual concerns. However, it is uncertain if perinatal providers are familiar with the tenets of palliative care. The range of medical conditions that affect families anticipating a fetal or neonatal death is wide, and this new domain of clinical practice and ethics has both similarities and distinct differences from other more established palliative care models (Feudtner & Munson,

2010). Caring for a family experiencing a life-limiting fetal diagnosis is a process requiring extensive team counseling and planning about obstetric and neonatal medical management (Munson & Leuthner, 2007). Moreover, the phenomenon of underutilized pediatric and neonatal palliative care points to complex issues associated with families, clinicians, organization, and values in our society, and it is unknown if similar challenges will present in the perinatal arena. Despite potential hurdles, health care professionals are ethically bound to offer compassion, guidance, support, and care. It is not clear if clinicians are confident about their ability to assume this role and if so, to what degree. Issues impeding feelings of confidence in providers can create hesitation in participating with palliative care modalities or providing patients with timely and appropriate referrals.

Since PPC is a newly emerging specialty, it is unknown if clinicians are comfortable providing health care for this unique patient population. Provision of palliative care in the perinatal period may be complicated by a wide array of emotions experienced by the expectant parents and the health care team as the pregnancy progresses and death becomes imminent. One of the most difficult aspects of the work of a healthcare provider is sharing information that is troublesome or potentially distressful for patients (Black, 2011). Over the course of a pregnancy affected by a terminal diagnosis, absolute prognostic uncertainty is a given and communication between providers and patients can be emotional, difficult, and stressful for all parties. Physicians, nurses and genetic counselors have reported distress and discomfort during encounters with families facing fetal or early neonatal death (Wool & Northam, 2011). There are no

clear evidence-based guidelines to inform clinicians in their care of families opting for PPC, creating potential practice challenges and an air of discomfiture. Although a large body of literature on perinatal loss is available, few studies exist that examine and validate the types of clinician responses that are beneficial to couples.

The goal of this study was to measure the perspectives of physicians and advance practice nurses (APNs), their comfort in providing and referring patients to PPC, and their reported confidence in delivering perinatal care when it moves into the palliative realm. The adoption of palliative care initiatives can provide connections between caregivers and families and result in a sense of purpose and meaning to ongoing clinical services even in the absence of being able to provide a cure. Physicians and nurses share commonalities in achieving this goal; however, their professional foci are somewhat distinct. It is unknown if these disciplines share similar perceptions and ethical viewpoints about PPC, and if so, to what extent. The ultimate desired outcome of this research is to promote confidence and comfort in physicians and APNs so they can deliver optimal, ethical care to families who choose PPC.

## Conceptual Framework

Provision of PPC involves an interdisciplinary approach aimed at supporting families from fetal diagnosis through pregnancy, birth, and neonatal death. The central obligation of nurses and physicians is to create the best possible experience for parents facing a lethal fetal diagnosis (Epstein, 2010). Ethical principles guide many of healthcare's activities and are familiar to a diverse group of practitioners; thus, a

bioethical framework will encapsulate this research design. To be valuable and effective, an ethical approach to palliative care must be responsive to the complex needs of families and be attentive to the moral practices of the healthcare community. Values commonly applied in medical ethics discussions (Beauchamp & Childress, 1994) are explicated in Table 1 (Hulac, 2007) and include select applications to PPC. This foundation will frame the moral obligations of the healthcare professionals and provide a platform for exploration of clinician perceptions, comfort level, and confidence.

Table 1 Ethical Principles and Application to PPC

| Ethical principle | Definition | Application to PPC |
|---|---|---|
| Autonomy | The principle of self-determination in which patients participate in decisions about their lives | Provide and clarify the families' understanding of case-specific information. Ensure informed consent |
| Beneficence and Non-maleficence | The principle placing the patient's best interest first and<br>The principle duty to first "do no harm"<br>Dictates obligation to protect patient safety and not cause injury | Identify values that each family brings to situation; respect wishes, clarify treatment options (or lack thereof) and use bioethical principles to guide conversations |
| Justice | The principle meaning to give each person or group what is "due" | Ensure equitable access to care and resources including access to staff members; palliative care protocols and support should be implemented by clinicians and supported by administrators |
| Dignity | The principle that every human has intrinsic worth | The patient, fetus and family have the right to be treated with respect and honor |
| Truthfulness and honesty | The principle of veracity in which the clinician provides information regarding diagnosis and care alternatives. | Recognize that some clinical scenarios involve irresolvable tragedies; Offer truthful information in a compassionate, gentle, sensitive manner |

Parental grief has been recognized as the most intense and overwhelming of all grief (Rando, 2004). To compound the loss of a desired, healthy, term infant, parents facing a life-limiting fetal diagnosis may experience a crisis of conscience because of the difficult and complex nature of the choices they are compelled to make (Sandelowski, 2005). Regardless of which path a family takes – ending or continuing the pregnancy – their decisions are difficult, complicated, and fraught with strain and emotion. They entail profound personal and psychological investment, and limited information is available about the ensuing emotional outcomes. The decision-making process can precipitate ethical, moral, and relational crises, and in many cases leaves an aching void from the loss of the fetus. Therefore, a healing environment needs to be created as couples face the overwhelming task of sifting through complicated medical information and making decisions about their future and that of their unborn child (Kobler & Limbo, 2011). Clinicians need the confidence to provide competent and compassionate care and deliver supportive services to families throughout their pregnancy course. Confidence is defined as the self-reported belief that the clinician is acting in a right, proper, or effective way when providing referrals and services to bereaved parents. An ethics framework enables clinicians to consider how the loss may impact the parent dyad, family system, and relevant social support structures. Responding to the needs of each family requires a proficiency in timely and sensitive communication skills and provision of emotional support through anticipatory guidance and appropriate referral skills. Clinicians lacking confidence may be hesitant to offer palliative care services, thus hindering the PPC

option for parents who are interested in continuing their pregnancy but feel a lack of confidence or support.

The Ethical Principles Framework depends heavily on the perceptions of the providers in their interactions with parents. Good palliative care involves the intersection of services intended to lessen the suffering of the family. Understanding the perceptions of clinicians and their comfort in providing care and referrals enables educators, researchers, and other stakeholders to address issues that currently may undermine a PPC model. Perceptions are defined as the perspectives, attitudes, and beliefs of clinicians as they pertain to various ethic-based aspects of perinatal palliative care. Identification of disciplinary differences and similarities related to comfort in delivering PPC will enable research findings to support practice changes and address the views provided by nursing and medicine. Investing in the discovery of clinician perspectives will provide insights and set a foundation for fostering their confidence when providing services to bereaved families.

The Perinatal Palliative Care Perceptions and Barrier Scale (PPCPBS) (Wool & Northam, 2011) was developed using an expert panel via a 3-round Delphi study. The research culminated in a piloted instrument found to be a psychometrically valid and reliable measure of perceptions and barriers. The perception portion of the PPCPBS instrument is based on the bioethical principles provided in Table 1.

## Methods

### Design

A cross-sectional survey design was used to obtain data online from a sample of physicians and advance practice nurses across North America so that inferences could be made about perceptions, clinician comfort, and confidence with PPC. The study was reviewed and approved by the University of Texas at Tyler Institutional Review Board and included an informed consent item at the beginning of the survey. The Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) was used to collect data. The survey was administered in the summer of 2011 using a computer-mediated, Web-based tool called Qualtrics. Emails, including a link to the survey, were sent out by the principal investigator to perinatal clinician colleagues across the United States. The email invitation directed clinicians to complete an online survey via Qualtrics with an incentive of a drawing for an Apple iPad. Additionally, an invitation to participate in the survey was posted on two perinatal list serves, and a flyer was distributed at a nursing conference directing individuals to the Qualtrics website. The methods derived a sample of 303 clinicians in 4 weeks: 66 physicians, 146 APNs, and 90 individuals who identified themselves as 'other'.

The aim was to derive a sample of at least 92 for multiple regression analysis to test a confidence hypothesis with six predictors. A minimum sample size of 50 +8 k was necessary (k is the number of predictors; so 8 x 6 = 42) (Green, 1991; Tabachnick & Fidell, 2007). The survey was available to clinicians in North America with computer access and Internet skills.

## Procedures

The original PPCPBS was developed using a Delphi technique with a panel of experts. It included two subscales and demographic questions. It was piloted in 2010 (n=245). The current 60 item PPCPBS includes demographic items, three 100-point visual analog scales (VAS) to measure confidence and comfort (personal and referral), and two 6-point Likert subscales measuring perspectives and perceived barriers. The 24 item perception subscale evaluates clinician thinking about ethical considerations in PPC and showed good internal consistency reliability in the pilot study of 0.77. The 22 item barrier scale examines organizational issues, like the availability of access to interdisciplinary team members, and personal barriers, like time constraints, and was reliable (alpha=.81) in the pilot study. For this study, a VAS was added to measure clinician confidence ranging from 0 (not at all confident) to 100 (very confident). Two VAS items were also added to measure the clinician's personal comfort with PPC and comfort in referring patients for PPC. The online survey used in this study had 61 items including 1 for informed consent. Data were downloaded and analyzed using SPSS 17.

# Results

## Sample

A total of 302 clinicians responded to the survey. Of those, the 70% completed by physicians (n = 66) and APNs (n = 146) are described in this report. The remaining 90 surveys were completed by other health care providers and are not included in this analysis. Most respondents (83.5%) were female (100% of nurses and 50% of

physicians). The sample was predominately white (89.6%). The majority (71.7%) of clinicians had greater than 10 years of experience. The largest proportion (52.4%) worked in an urban setting in academic teaching institutions (41%) and community hospitals (36.3%). The majority (86.9%) of respondents have cared for at least one family and as many as 200 families experiencing a life-limiting fetal diagnosis in the past five years. Table 2 summarizes the demographic features and practice characteristics of the sample.

**Exploratory Data Analysis**

Exploratory data analysis was done to evaluate parametric assumptions using methods recommended by Field (2009) and Mertler and Vannatta (2005). In this study, the 24 item perceptions scale performed better than in the pilot study with a reliability of 0.79 and the 22 item barriers scale also yielded a higher alpha reliability of 0.86. Sum scores were created for the perceptions and barriers scales and both variables were normally distributed with homogeneity of variance. The confidence, personal comfort, and referral comfort variables demonstrated mild skew and significant Kolmogorov-Smirnov tests so analyses were run and reported on both untransformed and transformed variables.

Table 2 Demographic, Training, and Practice Characteristics of Respondents

| Characteristics | No. of Respondents (212) | | |
|---|---|---|---|
| | Total | Nurses | Physicians |
| | | 146 (68.8) | 66 (31.1) |
| Race/ethnicity | | | |
| African American | 4 (1.9) | 0 (0) | 4 (6.1) |
| American Indian or Alaskan Native | 1 (0.5) | 0 (0) | 1 (1.5) |
| Asian | 7 (3.3) | 1 (0.7) | 6 (9.1) |

Continued on next page

Table 2 (Continued)

| | | | |
|---|---|---|---|
| Hispanic/Latino | 6 (2.8) | 5 (3.4) | 1 (1.5) |
| Native American/Pacific Islander | 2 (0.9) | 0 (0) | 2 (3.0) |
| White | 190 (89.6) | 139 (95.2) | 51 (15) |
| Other | 2 (1) | 1 (0.7) | 1 (1.5) |
| Gender | | | |
| Male | 31 (14.6) | 0 (0) | 31 (47) |
| Female | 177 (83.5) | 144 (100) | 33 (50) |
| Facility Location | | | |
| Rural | 28 (13.2) | 24 (16.4) | 4 (6.1) |
| Suburban | 73 (34.4) | 49 (33.6) | 24 (36.4) |
| Urban | 111 (52.4) | 72 (49.3) | 39 (59.1) |
| Clinical Setting | | | |
| Academic teaching hospital | 87 (41) | 50 (34.2) | 37 (56.1) |
| Community hospital | 77 (36.3) | 62 (42.5) | 15 (22.7) |
| Private practice | 32 (15.1) | 19 (13) | 13 (19.7) |
| Clinic/public health facility | 4 (1.9) | 4 (2.7) | 0 (0) |
| Other | 12 (5.7) | 11 (7.5) | 1 (1.5) |
| Professional Affiliation | | | |
| Obstetrician/gynecologist | | N/A | 11 |
| Neonatologist | | N/A | 38 |
| Perinatologist | | N/A | 5 |
| Family practice physician | | N/A | 2 |
| Certified Nurse Midwife | | 70 | N/A |
| Nurse Practitioner | | 33 | N/A |
| Clinical Nurse Specialist | | 13 | N/A |
| Other | | 23 | 10 |
| No. of Cases with Life-limiting Fetal Diagnosis in past 5 years | | | |
| None | 13 (6.1) | 13 (9.6) | 0 (0) |
| 1-10 | 126 (59.4) | 96 (71.7) | 30 (48.4) |
| 11-20 | 18 (8.4) | 10 (7.4) | 8 (12.9) |
| 21-30 | 14 (6.6) | 6 (4.4) | 8 (12.9) |
| >30 | 26 (12.2) | 10 (7.2) | 16 (25.7) |
| Not reported | 15 (7.0) | 11 (7.5) | 4 (6.1) |
| Years of Experience | | | |
| < 1y | 2 (0.9) | 2 (1.4) | 0 (0) |
| 1-5 y | 27 (12.7) | 12 (8.3) | 15 (23.8) |
| 6-10y | 26 (12.2) | 18 (12.3) | 8 (12) |
| >10y | 152 (71.7) | 112 (76.7) | 40 (60.2) |
| Not reported | 5 (2.3) | 2(1.4) | 3(4.5) |

## Professional Differences based on Demographic Data

Demographic data was analyzed to explore differences in perceptions and perceived practice barriers. Analysis of physician gender involved 31 females and 29 males. Based on gender, among physicians, no significant differences were noted in either overall perceptions ($t = .31$, $df = 58$, $p = .76$) or reported barriers ($t = -.50$, $df = 52$, $p = .59$). Items in the perception and barriers subscale were individually analyzed to determine differences by gender. Significant differences among physicians based upon gender on perceptions were found in three items, with higher mean scores for the male cohort in each of the following: 1) prenatal bonding may help bring closure for negative outcomes; 2) because the cost of palliative care to an organization may be greater than the cost of an early termination, PPC should not be offered; and 3) termination is ethically acceptable to me. The physicians' results did not reflect significant differences in any barrier items by gender. The nurse cohort did not include any males.

Race and ethnicity were examined, but inadequate group size undermined insight. There was a significant difference in barriers with urban practice locales reporting the most barriers followed by suburban workers and then rural workers. The rural work group was the smallest (n=23) but there was homogeneity of variance. There were no significant difference in perceptions by locale.

## Comparisons of Nurse and Physician Perceptions and Comfort with PPC

Clinician perspectives on principles related to PPC concepts are largely the same. Non-significant findings between physicians and APNs in perceptions were noted.

Further examination of scale items revealed significant differences in two perceptions. First, physicians and nurses differ on their perception that the option of ending a pregnancy in which the fetus has a life-limiting condition allows a family to heal faster ($U$ = 2.91, $z$ = -2.91, $p$ = .00, $r$ = -.20). Physicians (mean rank = 88.83) rank this item significantly lower than nurses (mean rank = 114.49) indicating that physicians are more likely to see termination as an alternative that allows a woman to heal faster when compared to a woman who opts to continue the pregnancy. Physicians (mean rank = 91.87), more so than nurses (mean rank = 112.43), were also more likely to perceive that continuing the pregnancy to birth when the neonate has a fatal condition puts an undue emotional burden on families ($U$ = 2.35; $z$ = -2.35, $p$ = .02, $r$ = -.18). However, despite these differences in views, physicians and nurses have fundamentally similar perspectives regarding the ethical constructs related to PPC.

Comfort with the idea of a palliative option in a life-limiting pregnancy situation and actual likelihood of referring families to PPC were also addressed. Results of the Mann-Whitney U reflect significant differences in personal comfort and referral comfort. Physicians are more comfortable with PPC (mean rank = 116.31) than nurses (mean rank = 98.37) $U$ = 3815, $z$ = -2.04, $p$ = .04, $r$ = -.14). Physicians are also more comfortable with referral (mean rank referral = 118.35) than their nursing colleagues (mean rank referral = 96.65; $U$ = 3617, z = -2.63, $p$ = .009, $r$ = -.18).

## Clinician Confidence

Clinicians also differed in their overall confidence in facilitating and managing PPC. Physicians were significantly more confident (mean rank = 129.40) than nurses (mean rank = 93.18) $U = 3029$, $z = -4.03$, p = .000, $r = -.88$. The large effect size (-.88) and clinical experience indicates that confidence is an important variable in PPC.

Exploratory data analysis was performed on the regression variables. Analysis was performed despite the non-normal distributions of the confidence, referral comfort, and personal comfort variables with plans to transform and rerun the regression. The assumption of multi-collinearity was not violated among the variables using the variable inflation factor (VIF) value parameters of values less than 10 and not substantially more than 1, indicating multi-collinearity is not a problem (Field, 2009). Mild heteroscedasticity was evident and may undermine generalizability.

Hierarchical multiple regression (MR) was used to test the hypothesis that clinician perceptions, reported barriers to PPC, years in clinical practice, referral comfort and personal comfort, and case history explain variation in confidence. Case history did not significantly improve prediction so it was deleted, and the MR was rerun. The best fitting model for predicting clinician confidence is a combination of the perceptions, barriers, years in practice, referral comfort and personal comfort. A significant regression equation was found ($F(5, 157) = 42.037$, $p < .001$) with an overall $R^2$ of .559. Tables 3 and 4 present the results of the best fitting model. Clinician perceptions, entered in the

first step, accounted for a small yet significant proportion of explained variance $R^2$ of .039, $p$ = .012. The perception variable was entered first because in practice settings, perceptions about palliative care precede the intent to implement such care; barriers are encountered after implementation is attempted. The barriers variable entered next and was a powerful predictor with an $R^2$ change of .33. As shown in the table, years in clinical practice and referral comfort made modest, yet significant contributions, to the model. Personal comfort with PPC, entered 5th, made a significant contribution with an $R^2$ change of .15.

Table 3: Summary of Hierarchical Regression Analysis for Variables Predicting Clinician Confidence (N = 212)

Model Summary [b]

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | Change Statistics | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | R Square Change | F Change | df1 | df2 | Sig. F Change |
| 1 | .197[a] | .039 | .033 | 27.712 | .039 | 6.472 | 1 | 161 | .012 |
| 2 | .607[b] | .369 | .361 | 22.529 | .330 | 83.610 | 1 | 160 | .000 |
| 3 | .631[c] | .399 | .387 | 22.056 | .030 | 7.932 | 1 | 159 | .005 |
| 4 | .650[d] | .422 | .407 | 21.693 | .023 | 6.362 | 1 | 158 | .013 |
| 5 | .757[e] | .572 | .559 | 18.715 | .151 | 55.280 | 1 | 157 | .000 |

a. Predictors: (Constant), Perceptions
b. Predictors: (Constant), Perceptions, Barriers
c. Predictors: (Constant), Perceptions, Barriers, Years in Clinical Practice
d. Predictors: (Constant), Perceptions, Barriers, Years in Clinical Practice, Referral Comfort with PPC
e. Predictors: (Constant), Perceptions, Barriers, Years in Clinical Practice, Referral Comfort with PPC, Personal Comfort with PPC

Table 4: ANOVA for the Regression Equation for Variables Predicting Clinician Confidence

| | Sum of Squares | df | Mean Square | F |
|---|---|---|---|---|
| Regression | 73621.466 | 5 | 14724.293 | 42.037[e] |
| Residual | 54991.810 | 157 | 350.266 | |
| Total | 128613.276 | 162 | | |

Data transformations to three variables that were not normally distributed (confidence, personal comfort, and referral comfort) and missing data management using nearby points in cases with less than 20% missing values did not make major differences in the model outcomes. The resulting and final hierarchical multiple regression resulted in a model $R^2$ of .56, F (5, 157) = 42.04, p < .000.

## Discussion

### Perceptions Identified

Findings from this study support a key concept in the conceptual framework regarding the importance of integrating ethical principles into patient care delivery. The findings indicate both disciplines share similar ethical perspectives that positively relate to PPC. The top ranking perceptions are outlined in Table 5, with higher means indicating more positive perceptions of PPC. Informing parents of palliative care options ranked first in both cohorts and are reflective of the ethical principles of informed consent and doing good, especially as it follows a perception that PPC is a "good" to be pursued.

Informed consent may reflect a desire for clinicians to avoid harm if the provision of intensive care is considered a net 'harm' and not in the affected baby's best interests. Coupled with autonomy and respect for persons – these being the parent(s) and the fetus as a potential person, was the principle of justice. Clinicians in this survey report that offering PPC when indicated is as important as offering curative care when indicated. Interestingly, clinicians also agreed that access to PPC services should not be influenced by its financial cost to an organization.

Table 5: Comparisons of top ranking positive perceptions of PPC

| APN rank order of perceptions | Mean | SD | N | MD rank order of perceptions | Mean | SD | N |
|---|---|---|---|---|---|---|---|
| Parents should be informed of PPC | 5.97 | 0.18 | 146 | Parents should be informed of PPC | 5.97 | 0.17 | 66 |
| PPC gives families time to bond with their fetus | 5.75 | 0.51 | 146 | PPC gives families time to bond with their fetus | 5.64 | 0.57 | 66 |
| Cost should not hinder access to PPC | 5.74 | 0.65 | 145 | Cost should not hinder access to PPC | 5.72 | 0.52 | 64 |
| PPC gives families a voice | 5.73 | 0.53 | 146 | PPC gives families a voice | 5.61 | 0.68 | 66 |
| Prenatal bonding brings closure for negative outcomes | 5.71 | 0.55 | 146 | Prenatal bonding brings closure for negative outcomes | 5.67 | 0.54 | 66 |
| PPC gives time to prepare for birth | 5.70 | 0.64 | 146 | PPC gives time to prepare for birth | 5.82 | 0.39 | 66 |
| PPC important as curative care | 5.67 | 0.64 | 146 | PPC important as curative care | 5.70 | 0.66 | 66 |

Principles of dignity, beneficence, and non-maleficence were articulated as providers acknowledged the multifaceted process of maternal-fetal attachment and the

relationship that develops between the fetus and the mother prior to birth (Brandon, Pitts, Denton, Stringer, & Evans, 2009). Providers viewed PPC as an affirmative option that gives families "a voice" and allows them to prepare for the birth and subsequent death of their child. Clinicians confirmed the opportunity to bond and spend time with an unborn child can be a beneficial result of PPC and agree it may help bring positive closure for families.

While there is no empirical evidence comparing the length of the healing process after loss of a pregnancy with fetal anomalies, physicians perceived termination to be a more healing alternative than PPC, differing significantly with their nurse colleagues. Perhaps this stems from the idea that termination of the pregnancy provides a family with more immediate closure, thus allowing them to move into a healing process sooner. Physicians differed with nurses in believing continuation of a pregnancy may place an undue emotional burden on families. More research is necessary to understand if a PPC option does indeed place an undue burden on families.

Palliative care involves both physicians and nurses making unique and positively synergistic contributions to the care of families in PPC. Overall, providers engaged in perinatal services report similar views and beliefs, supporting Epstein's (2010) qualitative research indicating physicians and nurses share common goals in neonatal EOL care. Both disciplines interpret ethical principles in tandem with positive views of PPC. This commonality provides a constructive platform for collaboration which providers can build upon when structuring PPC programs. These findings suggest how important it is to

ascertain the perspectives of clinicians and acknowledge their perceptions so that the similarities can be leveraged to provide ethical, compassionate services to families.

**Barriers**

Unfortunately, clinicians who value PPC and seek to provide support for families may quickly encounter barriers to providing the care. An independent t-test was used to compare the differences in physician and nurse reported practice barriers as measured by the barriers subscale. Higher scores are indicative of better practice environments, with fewer barriers. There was a significant difference in the practice barriers described by physicians (M= 97.23, SD= 10.54) and nurses (M= 88.87, SD= 15.97); t(154) = 4.16, $p$ = .000. These results suggest that physicians perceive fewer barriers than nurses and had more in common in terms of their perceived barriers. Both physicians and nurses perceive barriers in their practice settings and voice concerns over the lack of societal understanding and support for PPC. Clinicians share similar feelings of distress and helplessness when providing care to families experiencing a lethal fetal diagnosis. However, they differ significantly in other defined areas of practice, with nurses reporting more difficulty in forming PPC teams and garnering administrative support.

The differences in perceived barriers speak to the need to develop collaborative models in order to achieve standards in PPC health care delivery. The lack of available resources as reported by APNs suggests a potential roadblock to families who wish to receive PPC. Effective palliative care frameworks need to be developed to inform the

domain of PPC and provide a basis for the planning of service delivery and continuity of care. Such formal models allow clinicians to work confidently within a scope of practice that is reasonable and safe, enabling clinicians to feel comfortable in providing the ethical care which patients deserve. A study examining barriers in pediatric palliative care by Davies and associates (2008) confirms obstacles related to communication barriers and supports the importance of immediate initiation of palliative care when a life-limiting condition is diagnosed, even if prognosis is uncertain.

**Personal Comfort with PPC and Referral**

In addition to various practice barriers, confidence is undermined by limited experience, personal discomfort with the concept of PPC, and lack of comfort with referral to PPC. An innate human response to perinatal loss is sadness, often coupled with stress and a desire to minimize suffering. Rendering palliative care services can be emotionally demanding and lead to caregiver distress and discomfort. Engler and colleagues' (2004) study of neonatal intensive care unit (NICU) nurses and APNs also found less experience to be correlated with decreased comfort in providing EOL care. Further, NICU's with bereavement and EOL policies in place had staff that was significantly more comfortable with provision of such care, underscoring the importance of adequate administrative support for clinicians.

A novel approach to service delivery such as PPC will naturally include questions and unknowns related to core competencies and how best to implement them. Clinicians,

with their varying levels of experience and personal values, showed a wide range of responses in their comfort levels. Physicians are generally more comfortable with perinatal palliative care (M= 86.14, SD= 14.97) than nurses (M= 69.00, SD= 29.19); t(203) = 5.59, $p$ = .000. Many of the physicians who completed the survey were neonatologists who are accustomed to working with critically ill infants over a time continuum. Palliative care delivery is a recognizable concept in many NICUs nationwide. In contrast, the APN cohort consisted largely of certified nurse midwives and nurse practitioners.

While APNs often are experienced with perinatal loss and bereavement services, managing potentially complicated patient care issues over the pregnancy trajectory and within an unfamiliar model may be the reason nurses cited feelings of personal discomfort. Additionally, palliative care constructs may be unfamiliar to perinatal nurses who usually do not receive formal training in end-of-life (EOL) issues. These findings confirm the importance of education and the need to normalize processes, coherent with individual needs, so that APNs can provide comprehensive services to families.

Physicians were also significantly more comfortable with referring patients to PPC (M= 95.89, SD= 7.53) than nurses (M= 86.75, SD= 21.39); t(195) = 4.51, $p$ = .000. The practice of patient referral is less common in nursing. However, because PPC requires collaborative relationships, it will be necessary for APNs to become familiar with site and community resources available for patients anticipating a loss.

Interdisciplinary work with colleagues from social services, bereavement teams, and spiritual services has great potential for strengthening the level of care to families and providing an atmosphere of mutual professional support, which in turn may increase the comfort in referral practices.

**Confidence**

Clinicians in perinatal service lines do not, as a matter of routine, receive formal training in fetal EOL issues. As a result, there is wide variation in skills, knowledge and beliefs as providers interface with families who receive a life-limiting fetal diagnosis. The decisions families make are important and irrevocable and often have an added element of being time sensitive. These weighty issues entail considerable accountability in professional practice ethics and require clinicians to identify avenues to provide competent, confident service delivery. Several opportunities for modifying practice environments are available, allowing clinicians to participate in PPC models with more confidence, such as the consensus-based recommendations by Catlin and Carter (2002) relevant to neonatal palliative care and extendable into PPC. Interventions include 1) planning and education to begin palliative care services, 2) the importance in establishing relationships among community and tertiary centers, 3) optimal support of the neonate during the dying process, 4) family support, and 5) ongoing clinician support.

Anecdotally, families report positive experiences with formal PPC programs, but research is needed to provide insights into the experiences of families choosing to continue their pregnancy. Results will help clinicians perceive and understand the

meaning families attach to such experiences and provide information for future evidence-based practice. Secondly, the barriers currently reported by clinicians convey a need to support providers in their feelings of distress and discomfort when providing care to families facing an unexpected fetal diagnosis and a potentially lengthy grief process. Traditionally, little emphasis has been placed on engaging patients on a psychosocial or emotional level in medical education and training. Application of formal and informal educational strategies may result in increasing provider confidence. Meyer and colleagues (2009) found practical in-class teaching strategies an effective means to increase clinician confidence and improving communication skills and relational abilities. Several other studies support the idea that EOL educational programs boost provider confidence (Runkle, Wu, Wang, Gordon, & Frankel, 2008; Wilkinson, Perry & Blanchard, 2008). Mentorship and role-modeling are options especially suited for students and novice clinicians.

**Implications**

This study has both ethical and practical implications. First, this study represents the voices of clinicians responsible for caring for families expecting a pregnancy to have a poor outcome. No published studies were found in the scientific literature to describe the perspectives of perinatal clinicians or report on their comfort and confidence in delivering PPC services. Thus, the findings of this study will inform practice for nurses and physicians concerned with fostering positive PPC models for families wishing to continue their pregnancy. The study findings will add to the extant literature on palliative

care practice environments when EOL services need to move into the perinatal realm. Moreover, the findings support the conceptual framework and contribute to an understanding of how clinicians view their ethical ability to comfortably and confidently provide palliative care to families. It confirms the struggles many clinicians' experience during EOL care and begins to differentiate how nursing and medicine diverge on several important issues, such as the ability to provide referrals and how practice barriers are perceived and experienced. Future studies should examine cultural perspectives of PPC for both families and caregivers.

**Limitations**

The incidence of fatal diagnoses in pregnancy and the exposure of clinicians to the families are unknown, so it is difficult to evaluate the representativeness of the clinician sample accessed in this study to all clinicians involved in PPC. A limitation is the reluctance of some practitioners to talk about this situation since it has moral, religious, and political implications. Individuals may not want to be involved with such contentious issues and may wish to avoid it and defer participation in PPC research. A large representation of Caucasian respondents may also limit generalizability. The majority of respondents were generally positive in their perspective of PPC, and individuals who elected to participate may be different from non-participants. Despite these limitations, the large variance in confidence explained by the five variables (perceptions, barriers, referral comfort, personal comfort, and years in practice) advances science into an area in which little prior research exists. Experience levels are a static

variable, but the other variables are very amenable to educational and administrative interventions to improve PPC.

## Conclusion

Both medicine and nursing are fundamentally rooted in ethical principles. This study represents a beginning understanding of clinicians' perceptions regarding how these ethical principles interface with palliative care principles in the perinatal arena. It examines the confidence and comfort levels clinicians experience when providing care for families anticipating a poor birth outcome. Further studies are required to find ways to equip clinicians with the tools necessary to examine their personal comfort and professional confidence and find avenues to relieve them of the distress that may accompany working with families suffering perinatal loss. Much work is needed to develop and test the palliative care models across a variety of losses, age ranges, cultures, and socioeconomic groups.

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# Chapter 3 : **Clinician Perspectives of Barriers in Perinatal Palliative Care**

Abstract and Manuscript prepared for *Nursing Research*

## Abstract

*Background:* Perinatal palliative care (PPC) is an emerging specialty aimed at providing supportive services to families anticipating fetal or neonatal demise.

*Objective:* This study measured the barriers physicians and advance practice nurses report in providing and referring patients to perinatal palliative care.

*Method:* A cross sectional survey design using the Perinatal Palliative Care Perceptions and Barriers Scale © was administered using a Web-based tool. Recruitment was completed via email and flyer invitations and list serves. Physicians (n = 66) and advance practice nurses (n = 146) participated. T-test and Mann-Whitney U were used to examine differences in clinician-reported barriers to PPC.

*Results:* Physicians and nurses differ significantly in the barriers they report. Nurses expressed more obstacles at the health care systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative support. Physicians are more confident in their ability to counsel patients than nurses. Both disciplines express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about PPC.

*Discussion:* Cultivating an environment of collaboration and interdisciplinary sharing can benefit both caregivers and patients. Nurses have an opportunity to lead and promote PPC endeavors through participating in advantageous partnerships and research. Both disciplines may benefit from interventions directed at increasing their comfort in caring for patients in a palliative setting through targeted education and supportive staff services.

*Key Words:* Perinatal Palliative Care; Perinatal Hospice; Barriers

## Manuscript

Clinicians caring for parents who are anticipating delivery of a child who is not expected to survive are witness to a devastating event that accentuates parental uncertainty and emotional reactions. Families are rarely prepared for the bad news that comes after prenatal technology has unveiled a life-limiting fetal diagnosis (Garcia, Bricker, Henderson, Martin, Mugford, et al., 2002). Life-limiting conditions are those for which there is no reasonable hope of cure. Parents experience a convergence of stressors as news of such overwhelming diagnoses often catapults families into the unknown. Parents experience shock and grief as well as pressure to make decisions that have weighty implications (Hedrick, 2005; Statham, Solomou & Chitty, 2000). While fetal interventions are an option for some families, most parents are compelled to consider other alternatives, namely, medical termination or carrying a pregnancy to its natural end. Both of these choices can be difficult and painful. Regardless of which path families take, healthcare clinicians are often ill equipped to provide a full range of support for patients given an unexpected fetal diagnosis.

Families who wish to continue their pregnancies have an opportunity to participate in an emerging specialty called perinatal palliative care (PPC). This novel domain of clinical practice has grown out of expressed needs of patients and providers (Feudtner & Munson, 2009) and stems from clinician expertise and literature in the pediatric and neonatal fields. PPC is a philosophy of care aimed at providing supportive services to families who are anticipating a fetal or neonatal demise. Clinicians have an ethical obligation to respond to these families in a compassionate, thoughtful, yet realistic

manner. Studies focusing on the care of families facing a life-limiting prenatal diagnosis are limited and most of the current evidence on parental experiences is anecdotal.

In 2007, the most recent year for which data are available, the leading cause of infant death in the United States was congenital malformations, deformations and chromosomal abnormalities and accounted for 20% of all infant deaths (Mathews & MacDorman, 2011). The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics (2011) recently published recommendations to direct clinicians in their care for families expecting a baby with impairment. The recommendations state "the informed consent process should involve thorough discussion of the risks and benefits for both the fetus and the pregnant woman. The full range of options, including fetal intervention, postnatal therapy, palliative care, or pregnancy termination, should be discussed (p. e477)." As the palliative care alternative continues to move into formalized clinical practice, clinicians need information on how to best provide care for families.

Perinatal palliative care, also called perinatal hospice, is an emerging specialty recognizing the uniqueness of each family through thoughtful and compassionate application of care. Expectations and intentions of families who choose a PPC approach should be met with appropriate clinical and psychosocial responses which include extensive advance care planning and support. The primary goal of PPC is to help families with the process of making choices about pregnancy management and birth decisions while grieving their anticipated loss (Sumner, Kavanaugh, & Moro, 2006). In the PPC

model, clinicians respond to the physical, psychological, spiritual, environmental, and sociocultural needs of families to preserve dignity and promote quality of life for the unborn baby and family, starting at diagnosis and extending post-delivery, regardless of length of life.

## Literature Review

Irrespective of diagnoses and timing, palliative care of the fetus or newborn and their family share four discrete themes: 1) clear and consistent communication, delivered compassionately, 2) shared decision-making, 3) physical and emotional support during pregnancy and time of death, and 4) follow-up medical care and bereavement support (Williams, Munson, Zupancic, Kirpalani, 2008). Identification of practice barriers in PPC is necessary in order to guide clinician efforts to provide optimal care. In pediatric literature, clinicians have reported many barriers to providing palliative care including ethical and legal issues, fragmented care, inadequate assessment and management of symptoms, and false hope for cure (Himelstein, Hilden, Boldt & Weissman, 2004). Clinicians also report uncertainty in prognosis and the family's inability to acknowledge an incurable condition as frequent barriers in pediatric palliative care (Davies, et al., 2008). Neonatal palliative care (NPC), itself a growing specialty, faces challenges applicable to perinatal palliative care. NPC aims to manage infant pain and symptoms, determine the newborn's quality of life and best interest through a culturally sensitive, negotiated, family-centered approach, and provide psychosocial and spiritual support for family members (Carter, 2004). The 2003 Institute in Medicine Report with its focus on

palliation for children endorses NPC. However, implementation of NPC protocols is varied, and executing normalized care for neonates remains challenging. Williams and colleagues (2008) discuss barriers clinicians experience involving 1) cultural issues, 2) lack of adequate training and expertise, and 3) clinician discomfort. Nurses in a 2009 study by Kain and associates (2009) reported three salient barriers in NPC including 1) inadequate staffing to support palliative care practice, 2) a physical environment not conducive to palliative care, and 3) parental demands and technological requirements. In the perinatal setting, palliative care ideally begins at diagnosis and extends into the postpartum period, shifting family needs to a combination of inpatient and outpatient resources. Families may require NPC services as neonates with life-limiting diagnoses have been reported to live for unexpected periods of time after delivery. Care may be extended into home environments through hospice.

Examination of practice barriers to PPC services will enhance the development of a framework for future protocols and guidelines in practice environments. Many clinicians are not aware that there are documented benefits (Calhoun, Napolitano, Terry, Bussey & Hoeldtke, 2003), ways to help support parents (Sumner, et al, 2006), or programs to which they can refer patients who wish to continue their pregnancies (Kubelbeck, n.d.). Anecdotal feedback from colleagues in the United States supports challenges similar to those experienced in NPC related to uncertainty with birth and death trajectory, indecisiveness based on the unknowns, parents' lack of readiness to acknowledge a terminal diagnosis, limited palliative care education, and clinician

discomfort with fetal death. Clinicians need evidence-based information that supports them in guiding parents through the diagnostic implications and advance care planning services.

## Purpose of the Study

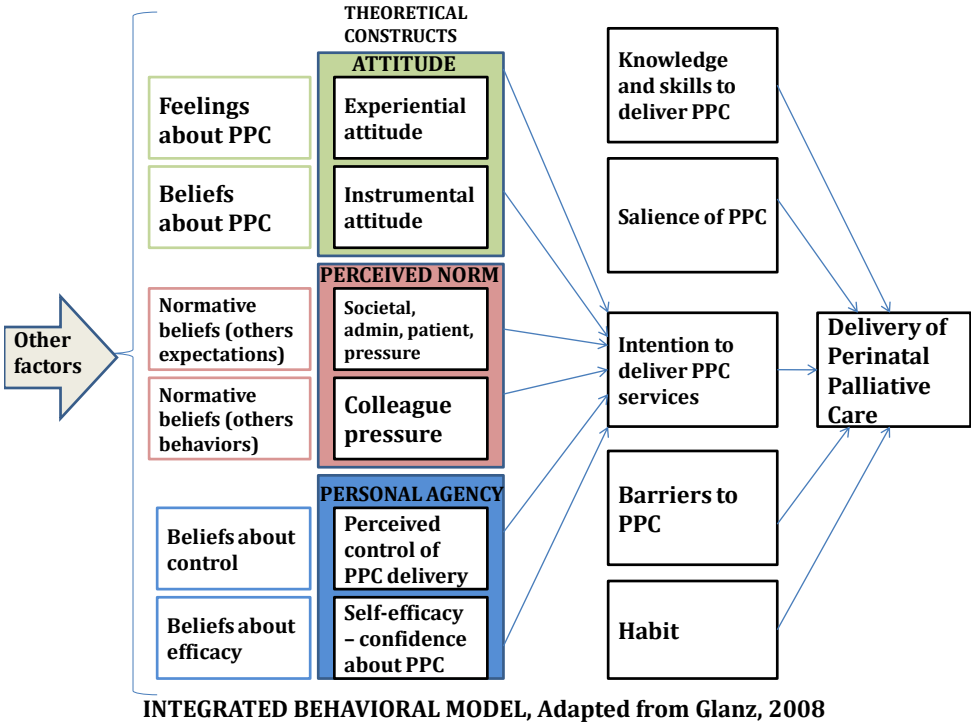
The purpose of the study was to understand the challenges facing physicians and advance practice nurses (APNs) who are on the front lines of caring for families facing the agonizing dilemma of dealing with a fetal terminal diagnosis. It was hypothesized that physicians and nurses experience differences in barriers. Understanding the obstacles to care delivery will enable clinicians, educators and researchers to target interventions designed to foster better understanding of the issues involved in PPC. The ultimate goal is to reduce barriers, advance understanding of PPC, and facilitate strong support systems that enable clinicians to provide optimal palliative care services. Properly rendered PPC will enable families who elect to continue a pregnancy to its natural end to manage the varied challenges and partner with professionals who provide support and understanding.

## Integrated Behavioral Model (IBM)

The Integrated Behavioral Model (IBM) includes constructs from the Theory of Reasoned Action and the Theory of Planned Behavior and posits that the most important determinant of behavior is behavioral intention (Fishbein & Ajzen, 2009). The IBM assumes a causal chain that links behavioral intentions and behaviors via 1) behavioral beliefs to attitudes, 2) normative beliefs to perceived norms, and 3) control beliefs to personal agency (Figure 1). Knowledge and skill, perceived salience, identification of

environmental constraints, and habits are additional components directly affecting behavior (Glanz, Rimer &Viswaneth, 2008). In other words, a behavior is most likely to occur if 1) the clinician has a strong intention to provide PPC services, 2) the clinician has the knowledge and skill to deliver PPC, 3) palliative care is seen as salient, 4) there are no serious barriers or environmental constraints preventing PPC delivery, and 5) the clinician has provided PPC previously.

Figure 1: Adapted integrated behavioral model




In a study by Wool (2011 dissertation) physicians and APNs acknowledged positive behavioral intention regarding delivery of PPC by expressing affirmative attitudes about palliative care in the perinatal setting. Clinicians reported varied levels of knowledge about PPC and articulated a desire to learn more about palliative care principles. Both

physicians and nurses underscored the salience of PPC. According to IBM theory, environmental constraints can impede clinician's behaviors, or their ability to deliver PPC. Therefore, this research aims to explicate clinician reported barriers to PPC. Findings from this study will be used to analyze and identify barriers so that targeted interventions can be developed that will lead to increased utilization of PPC services.

## Methods

### Design

A cross-sectional survey design was used to obtain data from physicians and APNs from the US with an aim to examine clinician perspectives of the barriers to perinatal palliative care delivery. The Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) was used to collect data (Wool & Northam, 2011). The survey was administered in the summer of 2011 using a computer-mediated, Web-based tool called Qualtrics. Emails with the link to the survey were sent out by the principal investigator to perinatal experts across the country. Snowball sampling was used to further distribute the survey to physician and nurses engaged in caring for expectant families. Invitations to complete the survey were also distributed at a nursing convention and to members of two perinatal list serves. Recruitment methods derived a sample of 66 physicians and 146 APNs in four weeks.

### Procedures

Data collection began following IRB approval from The University of Texas at Tyler. Purposive, non-random sampling was used and the survey was available to

clinicians in North America with computer access and Internet skills. Completed surveys were stored on the Qualtrics software and downloaded by the PI into SPSS version 17 for data analysis. Participants entered the survey through a hyperlink. Informed consent was provided at the start of the survey, and the opportunity to be the randomly-selected recipient of one free Apple iPad for completion of the survey served as an incentive. Participants could voluntarily provide an email address at the end of the survey if they wished to enter the drawing. No attempt at any time was made to connect responses with participants.

**Statistical Analysis**

Exploratory data analysis was done to evaluate parametric assumptions using methods recommended by Field (2009) and Mertler and Vannatta (2005). The 22 item barriers scale yielded a strong alpha reliability of 0.86. Sum scores created for the barriers scale were normally distributed with homogeneity of variance. Higher scores reflect more positive clinical and professional work environments with fewer barriers. Group comparisons between physician and nurse respondents included examination of clinician differences in perceived practice barriers. An independent sample t-test was calculated on the barriers subscale and a Mann Whitney U was calculated examining clinician differences in each individual barrier. The latter calculations were done to explore discipline-specific issues. Significant test results are reported with $\alpha = .05$.

## Results

### Sample Characteristics

A total of 212 clinicians responded to the survey. Most respondents (83.5%) were female (100% of nurses and 50% of physicians). The sample was predominately white (89.6%). The majority (71.7%) of clinicians had greater than 10 years of experience. The largest proportion (52.4%) worked in an urban setting in academic teaching institutions (41%) and community hospitals (36.3%). The majority (86.9%) of respondents have cared for at least one family and as many as 200 families experiencing a life-limiting fetal diagnosis in the past five years. Table 1 summarizes the demographic features and practice characteristics of the sample.

Table 1 Demographic, Training, and Practice Characteristics of Respondents

| Characteristics | No. of Respondents (212) | | |
|---|---|---|---|
| | Total | Nurses 146 (68.8) | Physicians 66 (31.1) |
| Race/ethnicity | | | |
| African American | 4 (1.9) | 0 (0) | 4 (6.1) |
| American Indian or Alaskan Native | 1 (0.5) | 0 (0) | 1 (1.5) |
| Asian | 7 (3.3) | 1 (0.7) | 6 (9.1) |
| Hispanic/Latino | 6 (2.8) | 5 (3.4) | 1 (1.5) |
| Native American/Pacific Islander | 2 (0.9) | 0 (0) | 2 (3.0) |
| White | 190 (89.6) | 139 (95.2) | 51 (15) |
| Other | 2 (1) | 1 (0.7) | 1 (1.5) |
| Gender | | | |
| Male | 31 (14.6) | 0 (0) | 31 (47) |
| Female | 177 (83.5) | 144 (100) | 33 (50) |
| Facility Location | | | |
| Rural | 28 (13.2) | 24 (16.4) | 4 (6.1) |
| Suburban | 73 (34.4) | 49 (33.6) | 24 (36.4) |
| Urban | 111 (52.4) | 72 (49.3) | 39 (59.1) |
| Clinical Setting | | | |

Continued on next page

Table 1 (Continued)

| | | | |
|---|---|---|---|
| Academic teaching hospital | 87 (41) | 50 (34.2) | 37 (56.1) |
| Community hospital | 77 (36.3) | 62 (42.5) | 15 (22.7) |
| Private practice | 32 (15.1) | 19 (13) | 13 (19.7) |
| Clinic/public health facility | 4 (1.9) | 4 (2.7) | 0 (0) |
| Other | 12 (5.7) | 11 (7.5) | 1 (1.5) |
| Professional Affiliation | | | |
| Obstetrician/gynecologist | | N/A | 11 |
| Neonatologist | | N/A | 38 |
| Perinatologist | | N/A | 5 |
| Family practice physician | | N/A | 2 |
| Certified Nurse Midwife | | 70 | N/A |
| Nurse Practitioner | | 33 | N/A |
| Clinician Nurse Specialist | | 13 | N/A |
| Other | | 23 | 10 |
| No. of Cases with Life-limiting Fetal Diagnosis in past 5 years | | | |
| None | 13 (6.1) | 13 (9.6) | 0 (0) |
| 1-10 | 126 (59.4) | 96 (71.7) | 30 (48.4) |
| 11-20 | 18 (8.4) | 10 (7.4) | 8 (12.9) |
| 21-30 | 14 (6.6) | 6 (4.4) | 8 (12.9) |
| >30 | 26 (12.2) | 10 (7.2) | 16 (25.7) |
| Not reported | 15 (7.0) | 11 (7.5) | 4 (6.1) |
| Years of Experience | | | |
| < 1y | 2 (0.9) | 2 (1.4) | 0 (0) |
| 1-5 y | 27 (12.7) | 12 (8.3) | 15 (23.8) |
| 6-10y | 26 (12.2) | 18 (12.3) | 8 (12) |
| >10y | 152 (71.7) | 112 (76.7) | 40 (60.2) |
| Not reported | 5 (2.3) | 2(1.4) | 3(4.5) |

The PPCPBS was built on pediatric and neonatal research and end of life (EOL) care with input from experts in perinatal palliative care. This report presents findings from analysis of the barriers items on the PPCPBS. The components of PPC measured by the instrument include 1) organizational and team support, 2) provider discomfort and stress in caring for families with a poor prenatal diagnosis, 3) time and organizational pressures, 4) expertise to provide a prognosis, counsel patients and consult experts,

including feeling valued and obtaining appropriate educational content, 5) societal understanding, and 6) access to medical services. The top ranking barrier given by both disciplines was a lack of societal understanding and support for perinatal palliative care. Providers also articulated similar feelings of discomfort by agreeing with statements such as "caring for families with a life-limiting fetal diagnosis is distressing" and "when further medical interventions are futile, I feel a sense of helplessness."

**Comparisons of Physicians and Nurses**

An independent t-test was used to compare the differences in physician and nurse reported practice barriers as measured by the subscale. Higher scores are indicative of better practice environments, with fewer barriers. There was a significant difference in the practice barriers described by physicians (M= 97.23, SD= 10.54) and nurses (M= 88.87, SD= 15.97); $t(154) = 4.16$, $p = .000$. These results suggest that physicians perceive fewer barriers than nurses and had more in common in terms of their perceived barriers.

Further examination using Mann-Whitney U statistics for each item in the barriers subscale revealed significant differences in 11 of 22 barrier items (Table 2). Nurses expressed more obstacles at the health care systems level, including the inability to secure administrative support and access interdisciplinary personnel for team meetings. Nurses were significantly less comfortable talking to expectant couples about the prognosis of a fetus or neonate who has a life-limiting diagnosis and felt less qualified than their physician colleagues to offer counseling. Additionally, APNs report more barriers in 1) finding time to counsel patients and 2) feeling pressured from administration when offering PPC services.

Table 2: Comparison of Physician and Nurse Barriers

| Barriers | Advance Practice Nurses | | | Physicians | | | Results |
|---|---|---|---|---|---|---|---|
| | Mean | SD | N | Mean | SD | N | Mann Whitney U |
| Insurance coverage | 5.68 | 0.79 | 145 | 5.69 | 0.61 | 64 | NS |
| Quick consult MFM | 5.34 | 1.10 | 145 | 5.62 | 0.58 | 65 | NS |
| Provider value | 5.25 | 0.91 | 146 | 5.20 | 0.75 | 66 | NS |
| Admin pressure | 5.17 | 1.08 | 139 | 5.49 | 0.87 | 65 | U=-2.03, p=.04 |
| Colleague pressure | 5.12 | 1.12 | 141 | 5.26 | 1.08 | 65 | NS |
| Time to offer options | 4.85 | 1.38 | 143 | 4.60 | 1.22 | 65 | NS |
| Organization support | 4.59 | 1.44 | 140 | 4.84 | 1.13 | 64 | NS |
| Time to counsel | 4.24 | 1.27 | 142 | 4.64 | 0.94 | 66 | U=-2.11, p=.04 |
| Admin supports PPC | 4.04 | 1.45 | 141 | 4.56 | 1.07 | 64 | U=-2.21, p=.03 |
| Team support PPC | 4.03 | 1.54 | 145 | 4.65 | 1.25 | 66 | U=-2.86, p=.00 |
| Access to PPC | 3.91 | 1.84 | 142 | 4.75 | 1.40 | 63 | U=-2.93, p=.00 |
| Provider uncomfortable | 3.82 | 1.32 | 142 | 4.37 | 1.36 | 65 | U=-2.81, p=.01 |
| Admin knows of PPC | 3.68 | 1.59 | 143 | 4.35 | 1.25 | 66 | U=-2.74, p=.01 |
| Education prepared | 3.65 | 1.30 | 145 | 3.50 | 1.43 | 66 | NS |
| Not qualified to counsel | 3.62 | 1.48 | 142 | 4.49 | 1.32 | 65 | U=-3.98, p=.00 |
| Provider helplessness | 3.55 | 1.30 | 146 | 3.70 | 1.20 | 66 | NS |
| Provider distress | 3.48 | 1.34 | 145 | 3.42 | 1.14 | 65 | NS |
| PPC meetings easy | 3.46 | 1.75 | 141 | 4.52 | 1.32 | 64 | U=-4.02, p=.00 |
| Termination allowed | 3.21 | 1.95 | 142 | 3.02 | 1.75 | 66 | NS |
| Lack team | 3.15 | 1.54 | 146 | 3.62 | 1.53 | 66 | U=-2.16, p=.03 |
| Societal support | 3.02 | 0.97 | 146 | 3.43 | 0.98 | 65 | U=-2.87, p=.00 |
| Societal understanding | 2.51 | 0.88 | 145 | 2.58 | 0.96 | 66 | NS |

## Discussion

Although PPC is a multifaceted, potentially complex mode of service delivery, clinicians are professionally obligated to provide supportive and compassionate services to families. A terminal fetal diagnosis is a life altering event that can impact families for years. Women remember the details of their loss for a lifetime (Capitulo, 2005) and the care they receive (or do not receive) will linger in their memories. Optimal EOL care requires interdisciplinary coordinated services and continuity of care. Findings from this study suggest clinicians face a considerable range of barriers in creating an environment conducive to healing.

Importantly, both disciplines may benefit from interventions directed at increasing their comfort in caring for patients facing fetal or neonatal death. The feelings of distress and helplessness clinicians report can be addressed by providing them with practical tools. Coping strategies, such as positively reframing the clinical case may be helpful to clinicians. Families choosing to carry to term express their experiences with PPC as overwhelmingly positive (Calhoun, et al. 2003) and this kind of parental feedback may be beneficial for clinicians. Rushton and associates (2006) suggest stress can be mitigated through interdisciplinary palliative care education and quality improvement programs. Additionally, staff support groups or regular interdisciplinary meetings to discuss difficult cases have been suggested as methods for alleviating stress (Levy, 2004).

### Barrier: Organizational and Team Support

Providers acknowledge organizational barriers as well as obstacles related to

interdisciplinary collaboration. Interestingly, when significant differences between provider groups were seen, nurses consistently experience barriers more than physicians. APNs express more difficulty when attempting to garner resources, access an interdisciplinary team, access palliative care services, and call a PPC meeting easily. Findings from this study indicate measures are needed to facilitate interdisciplinary communication and support. Papadatou and associates (2001) found cultivating constructive relationships within teams results in more satisfying experiences for nurses. Evidence suggests collaborative efforts have positive impacts on patient satisfaction and improved provider quality of work life (Baggs, 2005).

Some successful programs have utilized a nurse coordinator to oversee and arrange team meetings, manage referrals both in-house and in the community, and ensure continuity of care (Leuthner & Jones, 2007; Ramer-Chrastek & Thygeson, 2005). However, respondents from this study, the majority (70.5%) of whom were midwives and nurse practitioners, voiced barriers related to nurses having less authority to initiate and render interdisciplinary palliative services. Anecdotally, physicians are often perceived have more influence in healthcare systems, making them potentially well suited to champion PPC endeavors. Tubbs-Cooley and colleagues (2011) convey the importance of tailoring and 'selling' palliative care interventions to different groups of providers so that they are willingly and enthusiastically implemented. The Institute of Medicine supports an interdisciplinary response to palliative care, with nurses acting as a core part of the team (Field & Behrman, 2003). Relationships among team members and

partnerships across disciplines are necessary to operationalize PPC models of care so that families are the recipients of coordinated, compassionate services.

**Professional Barriers**

Having the time to counsel patients was seen as a hindrance by more nurses than physicians. Midwives provided the largest representation (48%) of APNs in this research. Midwives generally provide care prenatally in an office setting where time is limited and administrative pressure exists to see patients quickly and efficiently. Providing clinicians with information regarding regional palliative care programs will enable them to refer families to appropriate services.

Findings from this study suggest that physicians experience more confidence in their qualifications to counsel families about the prognosis of a fetus/neonate with a life-limiting diagnosis. Neonatologists and obstetricians are trained and accustomed to providing diagnostic and prognostic information. Their educational background and experience with medically sensitive diagnoses may enable them to be more comfortable talking to parents. Nurses, in contrast, are more likely to view the delivery of prognostic information outside their scope of practice. The discipline of nursing differs with the medical discipline in this regard since nurses are educated to be experts in diagnosing and treating a patient's ***responses*** to a particular diagnosis (Wiedenbach, 1963). Equipped with such a rich history of caring, nurses will have opportunities to lead PPC endeavors.

Targeted education has been shown to increase confidence (Wilkinson, Perry, & Blanchard, 2008). Classes can be taught to hone communication skills, practice

therapeutic patient-clinician role-modeling, and inform clinicians of research findings and supportive services available in their communities. In-house learning opportunities for clinicians to participate in PPC education and implementation can enhance confidence and the ability to provide good palliative care for families (Shiffman, Chambelain, Palmer, Contro, Sourkes & Sectish, 2008). Additional systematic study, improved education, and continued development of effective programs using multiple delivery methods can result in more compassionate delivery of services for parents.

**Societal Barriers**

Increased focus on patient autonomy and involvement in decision-making has resulted in some parents choosing to continue their pregnancies even in situations of terminal fetal diagnoses. Media representation of parents' experiences is quickly increasing as traditional news outlets carry stories of hope and healing for parents choosing to deliver to term (Kubelbeck, n.d.). Non-traditional venues such as You-tube and the Internet offer immediate access to information regarding the option of carrying to term (Choosing Thomas, n.d.). While these media messages may influence parents to continue their pregnancy, the attitudes of society in the US may not be in sync. Both physicians and nurses view a lack of societal understanding and support as barriers to PPC. Indeed, for many young Americans, both death and the concept of palliative care are unfamiliar and uncomfortable. Fear of the unknown and an inability to know how to respond to a family expecting a baby who will soon die may contribute to society's attitude about infant death. The provision and support of palliative services honors the

brief life of the newly born and forwards a healing environment, encouraging parents to find meaning despite their sorrowful circumstances. Clinicians have an opportunity to inform patients and their extended families about the positive experiences PPC can cultivate.

### Limitations

The sample of primarily white clinicians undermines generalizability of the findings. Research including a more diverse sample from racial, ethnic, and religious groups would foster insight into whether those variables impact clinician perceptions of barriers. While the sample size was adequate, additional study with more clinicians, particularly physicians since only 66 participated, would also strengthen the findings.

## Conclusion

Clinicians in this study reported many barriers to implementation of perinatal palliative care services. While attainment of such services may remain elusive, it is the obligation of providers to strengthen models of care which will improve patient outcomes. PPC requires an unswerving desire to be of service to families expecting an impaired child. Clinicians must confront and overcome social, organizational, and professional barriers. A willingness to accept that death is a part of life, even at such an early age, enables clinicians to convey compassionate, pragmatic and psychological support. Although some of these obstacles may be difficult to remove, many of them lend themselves well to interventions that can support provider confidence and competence while leading to improved patient care and outcomes.

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# Chapter 4 : **Summary and Conclusion**

## Evaluation of the Project

This research aimed to discover the perceptions, confidence and reported practice barriers in a new area of medicine called perinatal palliative care. Strengths of the study include usage of a newly developed instrument. The Perinatal Palliative Care Perception and Barriers Scale was developed using a Delphi technique with a panel of experts, enhancing its validity. In this study, the 24 item perceptions scale performed better than in the pilot study with a reliability of 0.79 and the 22 item barriers scale also yielded a higher alpha reliability of 0.86. The results of this research fill a major gap in an important area impacting both clinicians and grieving families.

The findings yield vital information that provides insights into the perceptions of clinicians on the front lines of caring for families in crisis. The clinician-reported perceptions of helplessness and distress can be mitigated through several measures. More research aimed at giving voice to families who carried their pregnancy to term is necessary, and its timely dissemination is paramount. The identification of practice barriers provides PPC advocates with information enabling them to recognize the challenges and address opportunities to remove obstacles from practice settings. Clearly, administrative barriers pose serious problems for clinicians, especially nurses. A variety of measures are warranted to address and reduce barriers.

Study weaknesses include the limited insight into clinicians with more varied racial and ethnic backgrounds. More study is needed to garner participation from

clinicians of diverse background. An increased number of physicians in future studies will enhance generalizability.

## Recommendations Based on the Findings

### Ha1: PPC practice barriers differ between physicians and APNs

Clinicians report many barriers to implementing effective PPC. Findings from this study give voice to clinicians' expressed feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. Both disciplines may benefit from interventions directed at increasing their comfort in caring for this special patient population. The feelings of distress and helplessness clinicians report can be addressed by providing them with practical tools. Coping strategies, such as positively reframing the clinical case may be helpful to clinicians. Families choosing to carry to term express their experiences with PPC as overwhelming positive (Calhoun, et al. 2003) and this kind of parental feedback may be beneficial for clinicians. Affirmative mentorship and role-modeling, education, and dissemination of information about the positive outcomes associated with PPC will also be useful. Rushton and associates (2006) suggest stress can be mitigated through interdisciplinary palliative care education and quality improvement programs. Additionally, staff support groups or regular interdisciplinary meetings to discuss difficult cases have been suggested as methods for alleviating stress (Levy, 2004). These findings emphasize the need for additional systematic study, improved education and support for clinicians, as well as development of effective policies that encourage the uptake of palliative care delivery.

**Ha2: There are differences in perceptions as they pertain to PPC between physicians and APNs**

Physicians and nurses have fundamentally similar perceptions regarding the ethical constructs of PPC. This result is reflective of clinicians' shared ethical principles, suggesting collaborative efforts to create formal PPC models can be built on a foundation suited to both professional groups. A shared vision will encourage sound consultation thereby defining future research strategies and practice environments. Recommendations for PPC modalities include an integrated structure which is initiated at diagnosis and allows for open, communicative relationships among the patient, family and health care team. Care delivery must include psychological as well as emotional support in tandem with physical care of the maternal-fetal dyad.

**Ha3: PPC perceptions, PPC barriers, years in practice, PPC case history, referral comfort, personal comfort, and personal experience with perinatal loss explain clinician overall confidence in their ability to deliver PPC in their setting**

Improving clinician confidence in the assessment and care of families in need of PPC services and having adequate resources for clinicians may prevent a diminished sense of accomplishment. Educational strategies are associated with increased confidence (Wilkinson, Perry & Blanchard, 2008). Classes can be taught to hone communication skills, practice therapeutic patient-clinician role-modeling, and inform clinicians of supportive services available in their organizations and communities. End of life issues are difficult for clinicians and there is the potential for professionals to suffer

from grief and moral distress (Rushton, et al, 2006). Clinicians reporting feelings of distress or discomfort can benefit from counseling, professional and social support, and education which encourages them to reflect on their practice and utilize coping skills to care for their personal well-being. Clinician confidence can be strengthened as future research endeavors aim to give voice to families who have decided to carry to term.

## Conclusion

This research represents a beginning understanding of clinicians' perceptions regarding how ethical principles interface with palliative care principles in the perinatal realm. It examines the confidence and comfort levels clinicians experience when providing care for families anticipating a poor birth outcome. The barriers clinicians report are significant, but many lend themselves well to interventions. Parental advocates and experts in EOL care can play a key role in informing clinicians as they work to confront and overcome social, organizational, and professional barriers. Further studies are required to find ways to equip clinicians with the tools necessary to examine their personal comfort and professional confidence and find avenues to relieve them of the distress that may accompany working with families suffering perinatal loss. Much work is needed to develop and test the palliative care models across a variety of losses, age ranges, cultures, and socioeconomic groups.

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Appendix A: Perinatal Palliative Care Perceptions and Barriers Scale ©

Informed Consent Form and Instrument

**Introduction**
Dear Clinician,

Greetings! You are invited to participate in a research study, the purpose of which is to survey physicians and advance practice nurses who provide services to expectant families. The aim of the study is to identify practice barriers and perspectives about perinatal palliative care, also known as perinatal hospice. A short 60 item survey follows this introduction. After completion of the survey you may enter a drawing to win a free iPad.

**Background and Definitions** Advances in fetal diagnostics have resulted in technologies that can screen and identify at-risk pregnancies. However, positive results from prenatal screening unfortunately often do not include a course of treatment for the fetus. A positive prenatal screening is one which identifies a problem in fetal development, and may be associated with conditions ranging from simple and treatable to life-limiting and lethal. When presented with a potentially lethal prenatal diagnosis, expectant parents are compelled to make difficult decisions based on limited options. Women may opt for a legal termination of pregnancy. However, there are women who do not wish to opt for termination, citing moral, ethical or personal reasons. Perinatal palliative care (PPC), also known as perinatal hospice, is an alternative model of care for families who wish to continue their pregnancy. Perinatal palliative care strives to neither hasten nor postpone fetal death. The goals of perinatal palliative care are:1. Help expectant parents with the process of making choices about pregnancy management, 2. Facilitate birth planning and after-birth care, 3. Provide comfort care to the neonate, and 4. Support families during pregnancy, birth, and bereavement. This survey is about PRENATAL aspects of care and the time period immediately following birth. It does NOT address immature or premature infants in a neonatal intensive care unit. Procedures This survey includes statements and questions about perinatal palliative care and asks for your perspectives as a clinician related to this model of care. It will be conducted with an online Qualtrics-created survey. At the end of the survey you may choose to enter a drawing for a free iPad.

Appendix A (Continued)

**Risks/Discomforts** Risks are minimal for involvement in this study. However, you may feel emotionally uneasy when asked to answer questions about this sometimes sensitive subject. Although we do not expect any harm to come upon any participants due to electronic malfunction of the computer, it is possible though extremely rare and uncommon.

**Benefits** There are no direct benefits for participants. However, it is hoped that through your participation, researchers will learn more about the perceptions and practice barriers of perinatal palliative care.

**Confidentiality** All data obtained from participants will be kept confidential and will only be reported in a conglomerate format (only reporting combined results and never reporting individual results). All questionnaires will be concealed, and no one other than then primary investigator and assistant researchers listed below will have access to them. The data collected will be stored in the HIPAA-compliant, Qualtrics-secure database until it has been deleted by the primary investigator.

**Compensation** While there is no direct compensation, at the completion of the survey you may enter a voluntary drawing to win an iPad. No effort at any time will be made to identify your personal information with your survey responses.

**Participation** Participation in this research study is completely voluntary. If you desire to withdraw, please just close your Internet browser.

**Questions about the Research** If you have questions regarding this study, you may contact Charlotte Wool at cwool@patriots.uttyler.edu. Questions about your Rights as Research Participants If you have questions you do not feel comfortable asking the researcher, you may contact Dr. Sally Northam, at snortham@uttyler.edu. Institutional Review Board approval was granted by The University of Texas at Tyler.

I have read and understand the above consent form and desire of my own free will to participate in this study.

- ❍ Yes
- ❍ No

Appendix A (Continued)

Parents experiencing a life-limiting fetal diagnosis should be informed of the option for perinatal palliative care

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Prenatal bonding may help bring closure for negative outcomes

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Perinatal palliative care gives families time to bond with their unborn child

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Recommending PPC may give parents the false impression of hope that the fetal diagnosis is not really fatal

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

Perinatal palliative care may cause undue stress in fathers

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Every fetus should have routine prenatal assessments regardless of prognosis

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Because the cost of palliative care to an organization may be greater than the cost of an early termination, PPC should not be offered

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

The option of ending a pregnancy in which the fetus has a life-limiting condition allows a family to heal faster

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

Continuing the pregnancy to birth when the neonate has a fatal condition puts an undue emotional burden on families

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Continuing the pregnancy to birth when the neonate has a fatal condition puts an undue emotional burden on society

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

The mother's physical health is the most important factor to consider in deciding whether to recommend perinatal palliative care

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

Perinatal palliative care gives families the opportunity to prepare for the birth and subsequent death of their baby

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Early in the pregnancy, when the fetus has been identified with a lethal condition, offering PPC would enhance their trust of me as a provider

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Perinatal palliative care gives parents time to spend planning their infant's birth

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

In my opinion, women who opt for PPC are at decreased risk for depression

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Perinatal palliative care can lead to undue suffering for the neonate

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

In my opinion, mothers who choose PPC grieve longer than those who opt to end their pregnancy early

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Termination is ethically acceptable to me

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

Perinatal palliative care prolongs maternal suffering

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Perinatal palliative care gives families a voice

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

I believe it takes a great deal of inner strength on the woman's part to continue a pregnancy when her fetus has a known life-limiting diagnosis

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

In the course of standard prenatal care, offering palliative care when indicated is as important as offering curative care when indicated

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Appendix A (Continued)

Continuing a pregnancy to birth when the neonate has a life-limiting condition puts an undue burden on a neonatal unit

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Perinatal palliative care is a way for couples to avoid dealing with the inevitable

- ❍ Agree Strongly
- ❍ Agree Moderately
- ❍ Agree Slightly
- ❍ Disagree Slightly
- ❍ Disagree Moderately
- ❍ Disagree Strongly

Please feel free to add comments about your perspectives on perinatal palliative care hereI receive educational content that teaches me how best to communicate with parents experiencing fetal death

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Society has an understanding of perinatal palliative care (i.e. perinatal hospice)

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

Society supports a care model of perinatal hospice

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Lack of an interdisciplinary team trained in providing PPC is a barrier at my facility

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

In my facility we have a health care team in which members of the team support PPC

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

In my facility termination of pregnancy is allowed

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

Caring for families with a life-limiting diagnosis is distressing for me

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

I feel a sense of value when attending to families carrying a fetus with a life-limiting diagnosis

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

I can quickly consult maternal-fetal medicine specialists to offer parents a fetal diagnosis, generally within several days

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

When further medical interventions are futile, I feel a sense of helplessness

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

In the daily course of my practice, I have enough time to counsel families facing a potentially fatal prenatal diagnosis

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

I am uncomfortable talking to expectant couples about the prognosis of a fetus/neonate who has a life-limiting condition

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Administrators at my facility know what perinatal palliative care is

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Administrators at my facility support perinatal palliative care efforts

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

I do not feel qualified to counsel families about PPC

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Offering palliative care options to expectant families is too time consuming

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Offering perinatal palliative care would cause me to feel pressured from administration

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Offering perinatal palliative care would cause me to feel pressured from colleagues

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

I feel insurance companies should cover PPC services

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

At my facility/clinic I have access to perinatal palliative care services

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

At my facility/clinic I could call a PPC meeting easily

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

I would feel supported by my organization when I offered perinatal palliative care services

- ❍ Always
- ❍ Very frequently
- ❍ Occasionally
- ❍ Rarely
- ❍ Very rarely
- ❍ Never

Appendix A (Continued)

Please feel free to add comments about practice barriers to perinatal palliative care in this box

On average, in the last five years, I have been involved in cases in which a lethal fetal diagnosis has been made

Total number of cases in 5 years
% resulted in termination (enter number please)
% resulted in continuation of pregnancy (enter number please)
% were referred for perinatal palliative care

Slide the bar to the right to answer

_____ Prior to taking this questionnaire, how familiar were you with the concept of perinatal palliative care or perinatal hospice?

Slide the bar to the right to answer

_____ How confident do you feel when caring for families experiencing a life-limiting fetal diagnosis?

Slide the bar to the right to answer

_____ Please rate your personal comfort with perinatal palliative care

Slide the bar to the right to answer

_____ Please rate your comfort with referring patients to perinatal palliative care

I work in:

- ❍ An academic teaching hospital
- ❍ A community hospital
- ❍ Private practice
- ❍ Clinic/public health facility
- ❍ Other (please specify) _____

Appendix A (Continued)

I am:

- ❍ A physician (please provide specialty) _____
- ❍ An advance practice nurse (please provide specialty) _____
- ❍ Other (please specify) _____

Slide the bar to the right to answer

_____ I have been in clinical practice _____ years

I am:

- ❍ A female
- ❍ A male

I consider myself (check all that apply)

- ❑ A spiritual person
- ❑ A regular attendee at religious services
- ❑ A humanist
- ❑ A spiritual agnostic
- ❑ An atheist

I have personally experienced perinatal loss in my immediate family (perinatal loss: miscarriage, stillbirth or death of a newborn up to the first month of age)

- ❍ Yes
- ❍ No

Slide the bar to the right to answer

_____ At my facility there are _____ number of deliveries per year

Appendix A (Continued)

I am

- ❑ African American
- ❑ American Indian or Alaskan Native
- ❑ Asian
- ❑ Hispanic/Latino
- ❑ Native American/Pacific Islander
- ❑ White
- ❑ Other (please specify) _____

When have you last received formal or informal information about perinatal palliative care or perinatal hospice?

- ❑ Please type in approximate date of PPC information and then check how you received the information _____
- ❑ Formal education in university setting
- ❑ Continuing medical education
- ❑ Journal article
- ❑ News or media outlet
- ❑ Colleague
- ❑ Other

I practice in:

- ❑ A rural setting
- ❑ A suburban setting
- ❑ An urban setting

Thank you very much for taking the time to complete this survey! If you would like to be in a drawing for an iPad, please type your email address here. If your name is chosen you will be contacted via email by the principal investigator and your gift will be sent to the address you provide. No attempt will be made to tie your responses to your email address, nor will your email address be given to anyone other than the principal investigator for the sole purpose of being in the drawing. Thank you again for your time!!! You are welcome to provide feedback in this comment box as well. Your thoughts, suggestions, and ideas are welcome!

Appendix B: Systematic Review of the Literature

Parental Outcomes after Diagnosis of a Fetal Anomaly

**Abstract**

Advancing technology has made detecting fetal abnormalities in the first and second trimester a reality. Few families are prepared for the difficult decisions that must be made if their unborn child is diagnosed with a life-limiting condition. Expectant parents are compelled to make decisions based on limited options. A systematic review of the literature is presented with an aim to inform clinicians of parental experiences and outcomes after diagnosis of a fetal anomaly. The review focused on patients given a diagnosis for fetal anomalies for the 40 year period from 1970-2010 using the key words fetal anomaly, congenital malformations, pregnancy termination, perinatal palliative care and perinatal hospice. Regardless of the option taken, women often experienced intense grief reactions. Both giving birth to a child with a life limiting condition or termination of pregnancy for fetal anomaly can be emotionally traumatic life events, both associated

with psychological morbidity. Non-aggressive obstetric management, allowing natural birth without life sustaining therapeutics, is an option for families. Couples presented with a coordinated perinatal palliative care model may opt to continue their pregnancy. Families who experienced perinatal hospice/palliative care report positive feedback but more research is needed to explore the psychological outcomes of this choice.

Key words: parental outcomes, fetal anomaly, pregnancy termination, perinatal palliative care, perinatal hospice

Despite improvements in obstetric and neonatal care in recent decades, neonatal mortality in the United States (U.S) in 2006 was 4.54 per 1000 live births and the infant mortality rate was 6.68 per 1000 live births[1]. Congenital malformations were the leading cause of death, attributing to 21% of the deaths. Differentiating prenatal diagnostics and prognostic assessments are increasingly detecting fetal abnormalities in the first and second trimester. Results from prenatal genetic testing provide information to families prior to the anticipated birth of their child regarding diagnosis, underlying etiology, potential treatment options, and probable outcomes[2]. The detection of anomalies through the use of sonography often does not include a course of treatment. Some degree of therapies may be available for a small portion of fetuses. However, for most families options include medical termination or carrying the pregnancy to a natural end.

## Background and Significance

The availability of technology has opened a new field of research including end-of-life decision-making after ultrasound diagnosis of a fetal abnormality[3]. Few families are ever prepared for the heart-wrenching decisions that must be made if their unborn child is diagnosed with a life-limiting condition. Expectant parents are compelled to make difficult decisions based on limited options. In a retrospective analysis of 53,000 pregnancies in the U.S., Schechtman, Gray, Baty, and Rothman (2002) report 72.5% of women opted for medical termination when presented with evidence of a fetal central nervous system anomaly[4]. From this report, it can be extrapolated that a quarter of these women choose to continue their pregnancy course.

Termination of pregnancy for fetal anomaly (TOPFA) is a management option in which medical or surgical measures are used to end the pregnancy[3]. In the United States, this medical response may be viewed as a socially stigmatized procedure resulting in additional tension during the decision-making process. Families who wish to continue their pregnancy are often served through non-aggressive obstetric management. They may also be candidates for perinatal palliative care (PPC), which is also referred to as 'perinatal hospice.' PPC is an emerging model of care addressing the expectations and intentions of families who choose to continue with pregnancy after their fetus has been diagnosed with a life-limiting condition[5].

Regardless of which path a family takes, these decisions are difficult, complicated and fraught with strain and emotion. They can precipitate ethical, moral and marital crisis, and in many cases leave an aching void from the loss of the fetus.

The importance of professional sensitivity to families enduring a crisis pregnancy cannot be underestimated. Clinicians are often in the situation of coming alongside these families to offer compassion, guidance, support and care. The purpose of this paper is to review relevant articles with an aim to inform clinicians of parental experiences and outcomes after diagnosis of a fetal anomaly.

## Search of the Literature

The review focused on patients given a diagnosis of fetal anomaly for the 40 year period from 1970-2010 using MEDLINE, CINAHL, Cochrane Database of Systematic Reviews and Psychology and Behavioral Sciences Collection. The following terms were searched individually and in combination: fetal anomaly, congenital malformations, pregnancy termination, perinatal palliative care and perinatal hospice. References from the retrieved articles were scanned to identify additional studies. Inclusion criteria included

- Life-limiting or fatal fetal diagnosis
- Parental decision-making
- Outcomes related to termination (TOPFA) or perinatal palliative care (PPC)
- At least 10 participants (to avoid small case reports)

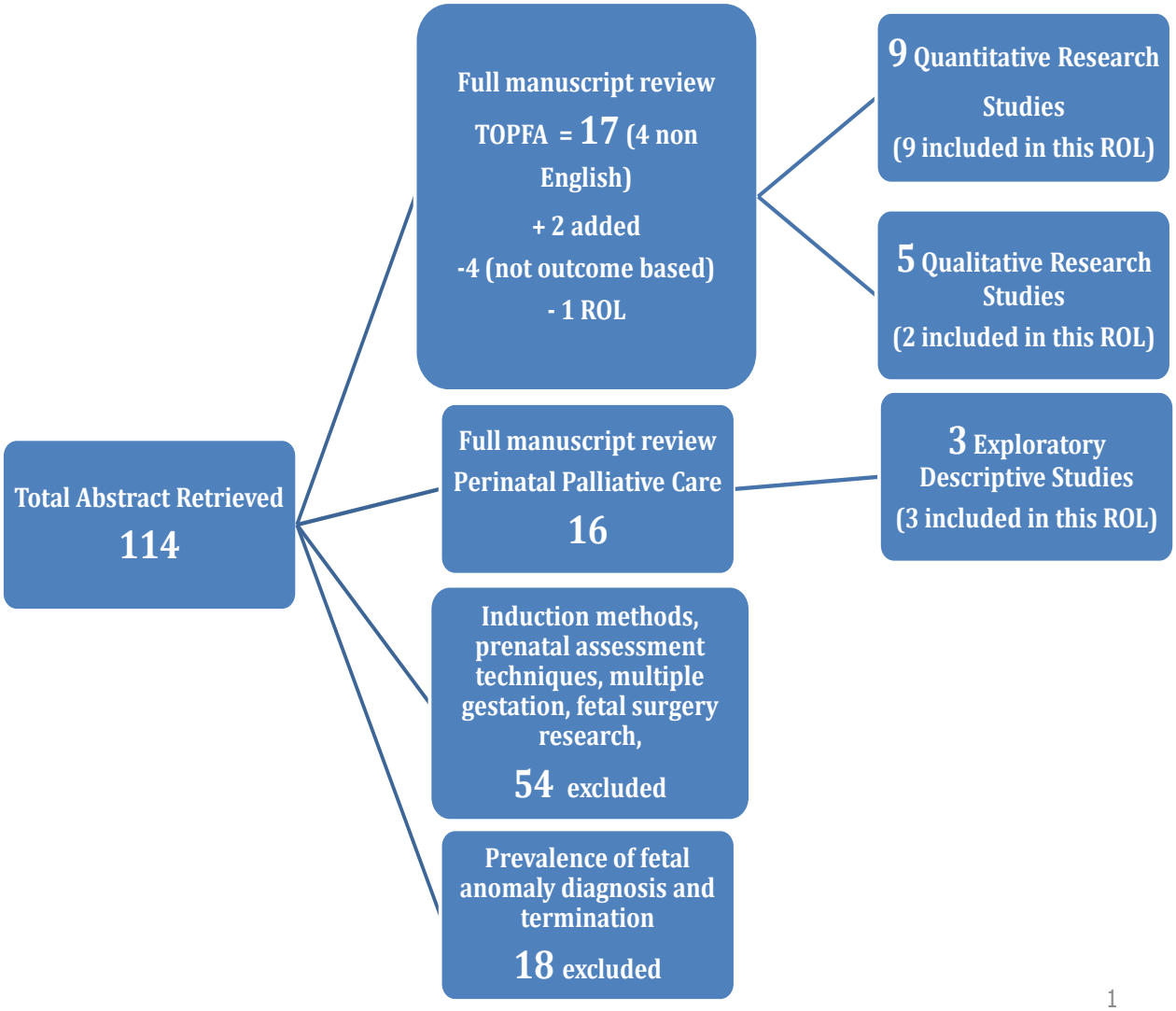
- Direct patient input, such as self-reported questionnaires, interviews or survey data

## Data Analysis

Initial search strategies identified 114 articles. Each abstract was reviewed and contained sufficient information to determine whether the study met inclusion criteria. Seventy-two of the studies were excluded as the abstracts had themes inconsistent with this review of the literature (Figure 1). Full manuscript review was completed for the remaining 33 articles, 14 of which qualify as research and addressed outcomes related to medical termination; 16 articles discussed perinatal palliative care, three of which were research articles (Evidence Table). Articles represented an international selection of participants.

Appendix B (Continued)

**Figure 1: Systematic Review of Literature Inclusion Schema**




1

Appendix B (Continued)

## Results

### Theme 1: Receiving the news

Advances in imaging techniques provide women and their partners an opportunity to view their fetus and be reassured of a healthy pregnancy. Couples are often unprepared for abnormal findings; and when bad news is delivered, they are ushered into a world of fear and uncertainty. While parents are committed to their pregnancy, they experience conflicting emotions to protect themselves, their future child, and their family from the potential burden of severe disability[3]. Upon initial diagnosis, couples may experience negative feelings associated with general psychological disturbance such as anxiety, anger, grief, loneliness, hopelessness, and guilt. These feelings, coupled with managing the practicalities of decision-making, leave parents with a sense of shock and bewilderment [6].

Women are asked to make choices in which a good fetal outcome is not an option. This situation creates significantly complex dilemmas for women and their families and places them on an unknown emotional trajectory. Regardless of which option is chosen, an abundance of research in past decades refers to the intense grief reactions women feel upon hearing bad news about their fetus and their painful experiences with the subsequent loss [7, 8].

**Theme 2: Opting for medical termination**

Nine studies using quantitative methods examined the mental health effects of TOPFA. A pilot study by Kersting and colleagues (2005) compared 83 women who were two to seven years post TOPFA and 60 women who were14 days post TOPFA to a control group of women who spontaneously delivered healthy infants [9]. Using the Impact of Event Scale, termination was associated with higher levels of trauma in both groups. Sadness, guilt, anger and a search for meaning were assessed with a German version of the Perinatal Grief Scale; while it was hypothesized grief reactions would diminish over time, results indicated no significant intergroup differences in the termination cohorts. Of note, 87.9% of the women studied would repeat their course of action, believing it to be preferable to delivery of a malformed fetus.

A second study by Kersting and colleagues (2009) compared psychiatric morbidity and the course of posttraumatic stress (PTS), depression, and anxiety in women who experienced TOPFA and women who delivered very low birth weight infants[10]. A control group of women who had delivered a healthy infant was also assessed. Women were questioned at 14 days, 6 months and 14 months. Posttraumatic stress and depressive symptoms were highest in women experiencing TOPFA. Of women diagnosed with PTS event, the TOPFA group had the highest clinically relevant scores at all three points in time. Depression and anxiety were higher in the TOPFA group than the control group across time. Interestingly, diagnoses in the TOPFA cohorts changed over time from a

spectrum of acute stress disorders, eating disorders, affective disorders and anxiety to exclusively depression and anxiety at 14 months post event.

In two large studies, Korenromp and colleagues used a series of standardized questionnaires to examine grief, PTS, and psychological and somatic complaints. The 2005a study measured outcomes in women two to seven years post event. Researchers found respondents generally adapted well to grief. Of the 254 women in the study 92% did not feel regret and 90% did not feel doubtful about their decisions. However, a number of participants had pathological scores for PTS (17.3%). Risk factors for poor psychological outcome included a low level of education and a low level of perceived partner support. More advanced gestational age at the time of termination was also associated with a higher level of distress[11].

Korenromp and associates (2009) examined psychological adjustment to termination at 4, 8 and 16 months, complementing the results of the 2005 research. Pathologic levels of PTS at 4 months were 46% which decreased to 20.5% at 16 months. Depression rates decreased from 28% to 13%. High levels of distress initially were strongly predictive of persistent disturbances. Other predictors included high level of doubt during decision-making, being religious, and advanced gestational age. With time however, negative impact of the termination seemed to pass [12].

Appendix B (Continued)

In a cohort study of 30 women, Davies, Gledhill, McFadyen, Whitlow and Economides (2005) noted prevalent and persistent psychological morbidity the first year after fetal loss. Using validated questionnaires, depression, grief, PTS, and emotional distress were measured at 6 weeks, 6 months and one year [13]. Combining results for first and second trimester terminations, 67% screened positive for PTS at six weeks, 50% at six months, and 41% at 12 months. Emotional distress rates were 53% at six weeks, 46% at six months, and 43% at 12 months. Grief rates were 47%, 31% and 27% and depression rates were 30%, 39% and 32% respectively.

Insights into the father's perception of this stressful pregnancy-related situation are less common. Two of the nine studies addressed paternal responses to TOPFA. One study retrospectively examined the psychological responses of 151 couples[14]. Grief, PTS, somatic complaints, anxiety, and depression following TOPFA were investigated. The study reports the majority of couples adapt well to their loss; however, years after the event, some respondents experienced responses such as PTS, depression and, to a lesser extent, grief. Men, as well as their partners, experience TOPFA more as a trauma than a loss event, and pathologic outcomes did not significantly differ between men and women with the exception of PTS. Determinants positively influencing psychological outcomes were the same in men and women.

They included a high level of education and good partner support, followed by earlier gestational age at termination, a diagnosis of incompatibility with life, and having other children. Of interest, couples rarely shared similar scores of high distress. This result has implications for educating and preparing families appropriately because couples may blame one another for not showing the same degree of distress during the coping process [14, 15]. Korenromp and colleagues (2007) measured psychological adjustment using several instruments four months post event. Irrespective of fetal diagnosis, some women and men suffered from PTS (44% and 22%, respectively) and symptoms of depression (28% and 16%, respectively)[16].

In a series of qualitative studies, McCoyd explored the experiences of 30 women living in the United States who had opted for TOPFA. Using grounded theory methodology with a convenience sample, McCoyd (2007) conducted intensive interviews [17]. The results give voice to many of the dilemmas women encounter as they bond and then have to separate from their fetuses. Women speak of unbearable stress during the decision-making process, the difficulty in processing through the stigma of termination, and the difficulties inherent in delivering an anomalous or disabled infant. Women feel society is unable to offer support and advocacy during this crisis, and reported that they carefully adjust disclosure to friends and family because of their own feelings of fragility and the fear of judgment from others.

Appendix B (Continued)

Participants describe deep and profound grief following medical termination. “The responsibility for decision-making complicates and seems to intensify this grief” (p 45) [17]. More than 75% of the women stated they “just wanted to die” and were unprepared for the protracted emotional pain they experienced following the event.

McCoyd (2009) writes of women’s encounters with the medical system from diagnosis through the aftermath of medical termination [18]. Interview responses were grouped thematically and presented in an unfiltered manner. Women experienced several challenges dictated by physician availability and insurance policies, including inadequate access to services and limited emotional support. For most of the participants, medical termination services were provided in unfamiliar settings with unknown care providers. The majority of women report difficulty getting the procedures covered by insurers. Some women had to travel out-of-state at significant personal expense to complete the procedure. The participants provided the following select recommendations to personnel engaged in medical termination of pregnancy: 1) develop protocols to ensure a supportive care provider, 2) provide continuity of care, 3) supply appropriate literature before and after the procedure, 4) offer insight and anticipatory guidance about what to expect, 5) create or collect and deliver keepsakes in a meaningful fashion, 6) conduct follow-up calls, and 7) provide genuine demonstrative compassion through listening, therapeutic touch, and “being with”.

Appendix B (Continued)

**Theme 3: Opting for non-aggressive obstetric management**

A limited body of research exists to inform clinicians of outcomes for women who choose to continue their pregnancy in light of a lethal anomaly. While non-aggressive obstetric management is a legitimate option for families, clinicians' expertise in managing the medical and psychosocial aspects of such cases may be limited. There is little published data for reference resulting in a lack of guidance to inform practice decisions. Only since 1997 has the literature presented a perinatal palliative care model which involves a coordinated multidisciplinary approach for families who wish to continue their pregnancy in the face of life-limiting diagnoses.

Of the 16 articles presenting a perinatal palliative care model, three exploratory descriptive studies were found. Calhoun and colleagues (2003) developed a PPC program and presented 33 patients with this option [19]. They found parents to whom comprehensive, multidisciplinary, individualized and informed counsel was given chose PPC 85% of the time. Of these, 61% delivered a live-born infant, and 39% experienced intrauterine fetal death (IUFD). No maternal morbidity was noted. Parental response to this model of care was reported as "overwhelmingly positive." In another exploratory study, 20 couples presented with a PPC option were followed. Forty percent chose to continue the pregnancy and pursue PPC. Six of the eight babies were live-born and lived between one and a half hours and three weeks. Parents provided positive feedback about

their decision and the care provided [20]. D'Almeida and associates (2006) engaged 28 families diagnosed with a prenatal congenital anomaly [21]. Seventy-five percent opted to participate in PPC with 76% delivering a live-born infant and 24% experiencing IUFD. As with Calhoun and associate's study, PPC was accomplished without any notable maternal morbidity and families expressing positive feedback.

## Critique

This review of the literature included nine quantitative and two qualitative studies examining the results of termination and investigating cohorts of patients in a rigorous scientific manner. Eight of the eleven TOPFA studies were conducted outside the US, and eight had the same three primary authors and included large sample sizes. International results need to be examined within cultural context, and generalizability may be impacted.

Three articles reported research on palliative care, one from England and two from the US. While the PPC exploratory studies offer an initial orientation with respect to parental choice when PPC is offered, the cohorts were small and further study of psychological and psychiatric outcomes of couples is warranted.

## Conclusion: Recommendations for Clinicians and Researchers

Results from this review of the literature emphasized that the experience of decision-making for a fetus with a life-limiting condition is a most difficult one. Both men and women suffered, and not always in the same way. Termination of an anomalous

fetus can be an emotionally traumatic life event. When compared to a spontaneous perinatal loss, TOPFA elicits similar grief reactions [8]. Women and their families may benefit from anticipatory guidance and coordinated and compassionate support services. Information should be given related to potential emotional responses post event related to mood, grief, and somatic symptoms [22]. Referrals for counseling may also be beneficial.

*Chosen loss* is a concept which has not been examined in the context of bereavement. Moreover, it remains largely unknown if women who choose to carry their pregnancy to its natural end exhibit negative psychological outcomes such as PTS, anxiety, guilt and depression at similar rates as those who choose medical termination.

Although limited information has been reported on perinatal palliative care, it is hoped that this alternative may prevent some of the aforementioned psychological grief that can be associated with termination. Perinatal palliative care is an alternative which seems to be well received by parents. However, clinician experiences with couples continuing pregnancy may be limited and doctors and nurses may be ill prepared to provide appropriate care [6]. A feeling of insecurity related to the lack of published data for reference can be addressed through research as a precursor to evidence-based practice. Examination of clinician attitudes and practice barriers to PPC services is indicated as is exploring a framework to guide clinical practice so providers are supported in their efforts to create a compassionate environment.

With dedicated resources, relevant training and formal guidelines, more parents may benefit from receiving a best-practices approach to identifying which alternative is most appropriate for each of these individual and complex situations.

Table 1: Evidence Table

| Article<br><br>Author(s) (Date)<br><br>Country | Sample Size (N)<br><br>Population | Variable/Method | Results | Strengths<br><br>Limitations |
|---|---|---|---|---|
| **Quantitative studies, TOPFA (9)** | | | | |
| Davies, V. Gledhill, J., McFadyen, A. et al. (2005) England | (30) women<br><br>N=14 first trimester TOPFA<br><br>N=16 second trimester TOPFA | Cohort study<br><br>Variables: psychological outcomes (general health, depression, perinatal grief, impact of event) at 6 weeks, 6 months and 12 months post termination | Psychological morbidity following TOPFA is prevalent and persistent; Grief lessens over time; high levels of emotional distress, depression and PTS noted in both groups at 6 weeks, 6 months and 12 months; Second trimester terminations had a significantly higher level of PTS at 6 weeks | Strengths: Examination of psychological issues in both first and second trimester; uses valid instrumentation measuring outcomes over time<br><br>Limitations: Data from one center; loss of follow-up in second trimester group; non-experimental |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Hunfeld, J., Wladimiroff, J., & Passchier, J., (1994)<br><br>Netherlands | (30) women with TOPFA ≥ 24 weeks gestation | Interviews and questionnaires examined perceived control over decision to terminate verses grief outcomes | 60% indicated perceived control over the induced delivery; 40% expressed a lack of control. The perception of having no control did not lead to a more intense grieving process as measured 3 months post event | Strengths: Offers interesting component of maternal perceived control; lack of control may counterbalance feelings of guilt or responsibility often associated with TOPFA<br><br>Limitations: Small sample size; interview results not provided; Cultural context relevant in this case due to legislative differences in the Netherlands versus USA |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Kersting, A., Kroker, K., Steinhard, J., et al., (2009)<br><br>Germany | (62) TOPFA<br><br>(43) VLBW<br><br>(65) control group; women who delivered healthy infants | Prospective longitudinal study. Variables assessed psychiatric diagnosis, posttraumatic stress, depressive and anxious symptoms at 14 days, 6 months, and 14 months in three groups | Fourteen days post event, 22.4% of TOPFA were diagnosed with psychiatric disorder compared to 18.5% of women after preterm birth and 6.2% in control group.<br><br>Corresponding values at fourteen months were 16.7%, 7.1% and 0%.<br><br>Short-term emotional reactions of TOPFA in late pregnancy appear to be more intense than preterm birth. | Strengths: Instruments used applicable to DSM-IV codes; control group; supports use of interventions to decrease psychological distress<br><br>Limitations: response rates at 14 months low; potential underestimation of psychological outcomes; control group of health term infants inadequate comparison – suggest control group of families diagnosed with anomaly who choose to carry to term |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| * Kersting, A., Dorsch, M. Kreulich, C., et al. (2005)<br><br>Germany | (83) women 2-7 years after TOPFA<br><br>(60) women 14 days after TOPFA<br><br>(65) women after full-term delivery of healthy baby | Pilot study comparing results (using the same instruments) of trauma and grief at 2-7 years post TOPFA with 60 women at 14 days post TOPFA and 65 women delivery healthy baby | PTS and grief reactions measured. Results indicate TOPFA is to be seen as an emotionally traumatic major life event which may lead to severe PTS and intense grief reactions detectable years later.<br><br>Perinatal grief scale non-significant results between TOPFA cohorts.<br><br>Impact of event scale indicated significance differences between control group and TOPFA cohorts | Strengths: Provide an initial indication of long-term PTS after TOPFA; included control group and comparative group<br><br>Limitations: 49% response rate may indicate those who did not response unable to do so due to increased suffering or unwilling to do so because of adequate coping. Instruments used were self-rated |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Korenromp, M., Christiaens, G., van den Bout, J., et al., (2005a)<br><br>Netherlands | (254) women undergoing TOPFA <24 weeks gestation | Cross-sectional study performed 2 to 7 years after TOPFA <24 weeks gestation. Variables include grief, PTS and psychological and somatic complaints using standardized questionnaires | Women generally adapt well to grief; 17.3% showed pathological scores for PTS 2-7 years later.<br><br>Predictors showing significant correlations with outcome measures: Grief predicted by level of education, gestational age and lethality; PTS predicted by level of education; perceived partner support had an independent effect on grief, PTS, anxiety and depression; doubt independently predicted by AGA, viability of fetus and presence of living children; no decrease in symptomology between 2 and 7 years post event | Strengths: Large study using valid instruments; standardized assessment over many years across hospitals with similar TOPFA policies<br><br>Limitations: does not include partners; lacks control group; questionnaires describe psychological symptoms, not psychiatric diagnosis |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Korenromp, M., Page-Christiaens, G., van den Bout, J., et al., (2009)<br><br>Netherlands | (147) Women undergoing TOPFA < 24 weeks gestation | Longitudinal study with validated self-completed questionnaires; Variables included grief, PTS, general psychological malfunctioning and postnatal depression assessed at 4, 8, 16 months; also used new questionnaire to assess pressure during decision making, regret, and partner support | Late onset of problematic adaptation was infrequent.<br><br>Four months following TOPFA 46% of women show pathological levels of PTS, decreasing to 20.5% after 16 months. Depression figures are 28% and 13% respectively.<br><br>The four month outcome was the most important predictor of persistent impaired psychological outcome.<br><br>TOPFA has significant psychological consequences for 20% of women up to > 1 year.<br><br>Strong feelings of regret mentioned by 2.7% of women. | Strengths: Large study using valid instruments; offers insight to psychological morbidity over time. Investigation of risk factors for problematic outcome gives clinicians information to improve care before and after TOPFA.<br><br>Limitations: Lacks control group; questionnaires describe psychological symptoms, not psychiatric diagnosis |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Korenromp, M., Page-Christiaens, G., van den Bout, J., et al. (2005b)<br><br>Netherlands | (151) Couples | Cross-sectional, retrospective study (using questionnaires) to examine psychological responses to TOPFA in both men and women to explore risk factors for poor psychological outcomes and interactions. Variables: parental age, educational level, being religious, additional children, gestational age at time of assessment, method of TOP, severity of anomaly, experience of life events 2 years prior to TOPFA, time elapsed since TOPFA, level of perceived partner support | Majority of couples adapt well without evidence of psychopathology.<br><br>Mutual influence between the partners in the grieving process noted; partners never showed pathological level of poor outcomes simultaneously.<br><br>Problematic responses, years after the event present in some couples, primarily PTS and depression. Grief reactions lessen over time. TOPFA viewed as more a trauma than a loss event; scores on psychological outcome measures significantly higher in women than men.<br><br>Determinants of positive outcome include high level of education and good partner support. | Strengths: Large number; Both genders included in study; used valid questionnaires; diversified study examining outcomes inclusive of men.<br><br>Limitations: 23% of women excluded from study due to partner's lack of participation; retrospective assessment of perceptions may be vary depending on current mood and therefore influence results |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Korenromp, M., Page-Christiaens, G., van den Bout, J et al., (2007)<br><br>Netherlands | (217) women<br><br>(169) men | Prospective cohort completed standardized questionnaires 4 months post TOPFA.<br><br>Variables measured by the Inventory of Complicated grief, Impact of Event Scale, Edinburgh Postnatal Depression Scale and the Symptom Checklist-90 | Women and men levels of PTS 44 and 22% respectively; symptoms of depression were 28 and 16% respectively.<br><br>Determinants of adverse effects: high level of doubt during decision period, inadequate partner support, low self-efficacy, lower parental age, being religious and advanced gestational age.<br><br>2% of women and 1% of men regret the TOPFA decision | Strengths: Large sample size using valid instrumentation to measure variables;<br><br>Limitations: study group highly educated; maternal age $\geq$36. Lack of information on the non-response group may have caused selective non-response; retrospective assessment of perceptions may be vary depending on current mood and therefore influence results |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| Zeanah, C., Dailey, J., Rosenblatt, M., et al. (1993)<br><br>USA | (23 women with TOPFA)<br><br>(23 women with spontaneous loss) | Case control study using Perinatal Grief Scale and Beck Depression Inventory 2 months post event; Variable of age of women and gestational age also examined in light of grief response | Women opting for TOPFA experience grief as intense as those who have spontaneous loss.<br><br>No relationship between gestational age and depressed mood, grief, difficulty in coping or despair. Only maternal age correlated significantly with grief, difficulty coping, despair and depressed mood. Younger women were more symptomatic.<br><br>Women who elected TOPFA saw and held their babies and reported that this was a painful but helpful aspect of the experience | Strengths: Used control demographically similar control group who experienced spontaneous loss; used validated measures of grief; assessed uniformly at 2 months post event<br><br>Limitations: Examines early adaptation only; small sample size increasing potential for Type II error; symptoms of reported grief potentially explained by premorbid functioning; selection of volunteer participants may affect findings |

Table 1 (Continued)

| Perinatal Palliative Care Studies (3) | | | | |
|---|---|---|---|---|
| Breeze, A.C., Lees, C. C., Kumar, A., et al. (2007)<br><br>England | (20) Women carrying newborns prenatally diagnosed with lethal anomalies after 18 weeks gestation | Exploratory descriptive study examining number of women who chose PPC when offered | 40% of families opted for PPC. Expressed positive feedback about their choice;<br><br>Uncertainty in predicting fetal outcomes and delivery times evident | Strengths: Informs clinicians of family desire and benefits of PPC<br><br>Limitations: small sample size; non-experimental; psychological outcomes not measured |
| Calhoun, B., Napolitano, P., Terry, M., et al., (2003)<br><br>USA | (33)<br><br>Patients carrying a fetus with a lethal anomaly | Exploratory descriptive study completed after development of a perinatal hospice program; parents presented with options. Patient use of the new service was evaluated; pregnancy outcomes also evaluated | Parents given comprehensive, multidisciplinary, individualized and informed counsel perinatal hospice care chose it 85% of the time. Of these 61% delivered a live-born infant and 39% experienced IUFD. No maternal morbidity was noted.<br><br>Parental response to perinatal hospice "overwhelmingly positive" | Strengths: Collects and presents data regarding number of families opting for perinatal hospice; military sampling indicative of diverse sampling<br><br>Limitations: Follow up questionnaires or surveys missing; non-experimental |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| D'Almeida, M., Hume, R. J., Lathrop, A., et al., (2006)<br><br>USA | (28)<br><br>Newborns prenatally diagnosed with lethal anomalies | Exploratory descriptive study examining number of women who chose PPC when offered comprehensive support; number experiencing IUFD; number of live births, preterm births; mode of delivery and length of survival of live-born neonate | 75% opted for PPC with no notable maternal morbidity; 76% delivered live-born infants who lived between 20 minutes and 256 days. | Strengths: One of the first studies of its kind to formalize PPC model and explore outcomes<br><br>Limitations: need to examine psychological and emotional outcomes of patients, families, providers; non-experimental |

Table 1 (Continued)

| Qualitative studies, TOPFA (2) | | | | |
|---|---|---|---|---|
| McCoyd, J.M.<br><br>(2009)<br><br>USA | (30) women's encounters with medical personnel during diagnosis and aftermath of TOPFA | Exploratory convenience sample ; Unstructured intensive interviews (followed by email interviews) soliciting feedback on decision-making and grieving examined themes from experiences of women and feedback from women regarding what they want from the medical profession from diagnosis through bereavement | Themes revealed:<br><br>Preparedness matters; Access to services for termination and emotional support are limited; Barriers include scarcity of surgeons and insurance challenges; Termination procedures vary geographically; Provider sensitivity and support inconsistent; Women provide advice to professionals | Strengths:<br><br>Rich, largely unfiltered data set provides unique insights to women's experiences and perceptions of medical personnel;<br><br>Thorough data analysis through use of coding<br><br>Limitations:<br><br>Inability to generalize finding broadly; cultural context not assessed; homogeneity of race, age and socioeconomic status |

Table 1 (Continued)

| | | | | |
|---|---|---|---|---|
| McCoyd, J.M.<br><br>(2007)<br><br>USA | (30) women's experiences of pregnancy loss within the framework of society, medical culture, and relationship with family and friends | Exploratory convenience sample ; Grounded theory methods;<br><br>Unstructured intensive interviews (followed by email interviews) soliciting feedback on decision-making and grieving within the framework of expectations and numerous dilemmas | Mythic expectations surround prenatal testing; intensive grief reactions following TOPFA (22/30 "just wanted to die")<br><br>Excruciating dilemmas point to struggling and suffering throughout continuum from diagnosis - years after termination | Strengths: Rich data set elaborates in processes involved in TOPFA including mythic expectations, dilemma's of bonding, testing, choice, identity, disability, story, support<br><br>Weaknesses: Inability to generalize finding broadly; cultural context not assessed; homogeneity of race, age and socioeconomic status |

* Not part of original retrieval; added after review of references

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## Appendix C: The Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) Instrument©: Development and Validation

Palliative care has traditionally been framed against the background of the elderly in the last stages of life. Moving the discussion into the neonatal arena is both painful and emotion-laden. The public wants to visualize the culmination of pregnancy as a healthy baby welcomed into a loving family. When this outcome is not possible, health providers are placed in the midst of a very stressful and emotional situation. The goal of this study was to develop an instrument for measuring health provider perspectives on perinatal care when it moves into the palliative realm. The desired outcome was to make palliative measures meaningful and healthy for the family and the providers involved in a difficult situation.

Despite improvements in obstetric and neonatal care in recent decades, the US neonatal mortality rate in 2006 was 4.54 per 1000 live births and the infant mortality rate was 6.68 per 1000 live births[1]. Congenital malformations were the leading cause of death, attributing to 21% of these cases. Advanced diagnostic technology, coupled with earlier and more effective assessment by specialists, have made it possible to detect fetal abnormalities in the first and second trimester. Results from prenatal genetic testing provide information to families before the birth of their child regarding diagnosis, underlying etiology, potential treatment options, and probable outcomes[2]. The detection

of severe anomalies often does not include a course of treatment, although some degree of therapies may be available for a small portion of fetuses. Most parents anticipating a child with life-limiting anomalies are faced with the decisions ranging from medical interruption of the pregnancy to maintaining the pregnancy to term.[3]

The availability of technology has opened a new field of research including end-of-life decision-making after a prenatal diagnosis of a fetal abnormality. Few families are ever prepared for the difficult decisions they are compelled to make when given a life-limiting prenatal diagnosis. Women who wish to continue their pregnancy have an option to experience non-aggressive obstetric management. They may also be candidates for perinatal palliative care (PPC), also referred to as perinatal hospice. The primary goal of PPC is to help families with the process of making choices about pregnancy management and birth decisions. It includes facilitating advanced care planning and after-birth care that incorporates the family's cultural mores and their personal and religious beliefs. The purpose is to assist families in preserving hope while preparing for birth and grieving their anticipated loss[4]. Only since 1997 has the literature presented a PPC model which involves a coordinated multidisciplinary approach addressing the expectations and intentions of families who wish to continue their pregnancy[5, 6]. Continuing a pregnancy with a life-limiting fetal diagnosis was seen as a viable and safe alternative by parents who reported positive feedback about their decision to participate in formal PPC programs[7-9].

## Significance

While non-aggressive obstetric management in life-limiting fetal diagnosis is a legitimate option for families, clinicians' expertise and confidence in managing the psychosocial, emotional and spiritual aspects of such cases are limited. No consensus currently exists on standardized definitions or supportive practice models for PPC. There are little published data for reference resulting in a lack of guidance to inform clinicians. A 2009 report by Kains and associates[10] explicates three salient barriers to a neonatal palliative care model. Neonatal nurses identified 1) inadequate staffing to support palliative care practice, 2) a physical environment not conducive to palliative care, and 3) parental demands and technological requirements. Anecdotally, practice barriers to PPC exist and a lack of awareness has been implicated as a barrier[4]. Additional research is needed to validate the practice environments, clinician attitudes and beliefs, administrative support structures, and perceived barriers to PPC. Instrument development and evaluation research were intended to be a first step in understanding clinician perceptions and practice barriers of PPC. Institutional Review Board approval was received for both stages of the study: Stage 1: the Delphi study, and Stage 2: pilot testing and psychometric evaluation.

Appendix C (Continued)

**Stage One: Delphi Study**

The first step in the development of the instrument included a comprehensive literature search identifying issues in the broader arena of palliative care and perinatal loss to discover potential linkages between clinician challenges and patient needs. This was completed and published in *Advances in Neonatal* care in the eleventh edition. Neonatal palliative care trends, prenatal diagnostics, and emerging issues in cases of life-limiting fetal conditions were also examined. Instrument development entailed organizing these themes into categories using a principle-based ethical conceptual framework. The ethical principles of beneficence/non maleficence, justice, autonomy, and respect for human dignity guide much of the healthcare sector and are familiar to a diverse group of practitioners. This interdisciplinary aspect of the instrument made it general enough to use with a cross-discipline network and yet specific enough to bring clarity to the areas in which providers offer their perceptions of PPC. Preliminary validity for the instrument was established with a small cohort of multidisciplinary experts who provided feedback on the initial draft which included 44 statements in five categories and additional open ended items.

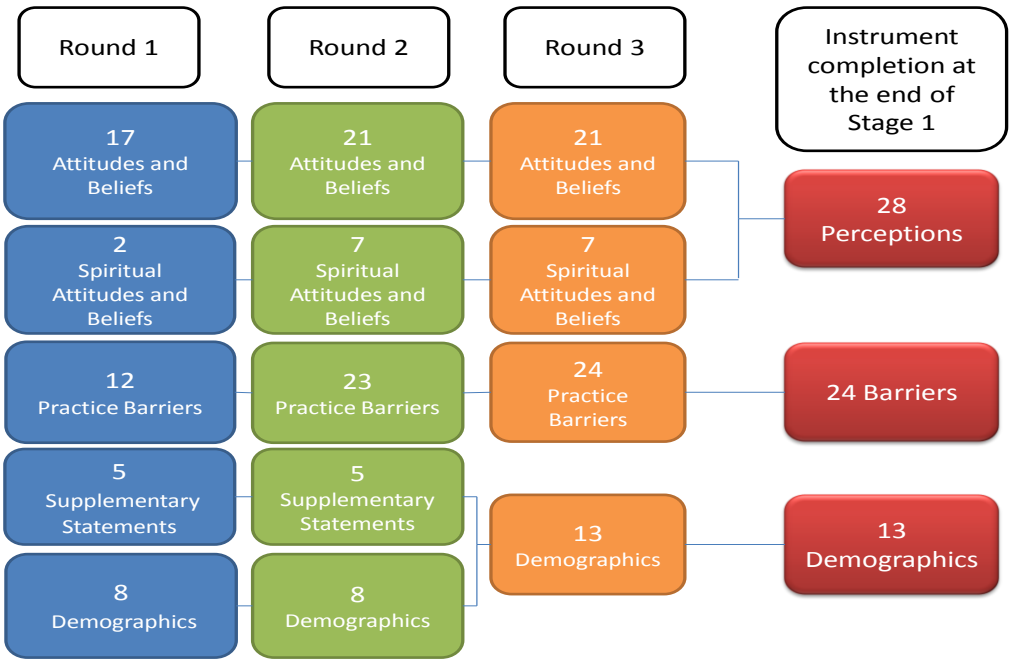
The Delphi technique is particularly helpful for its ability to structure and organize group communication to reach consensus[11, 12]. The Delphi technique is accomplished through a series of data collection sessions called “rounds.”

The beginning round involves structured input from contributors on a general topic. Subsequent rounds involve accumulating, collating, and collapsing input and returning it in the next round to the participants for verification of accuracy and further feedback until a general consensus is reached. This PPC study involved three rounds of feedback from participants to develop a series of sequential questionnaires which were modified based on the feedback provided. The work culminated in an instrument called the Perinatal Palliative Care Perceptions and Practice Barriers Scale (PPCPBS).

Invitations for stage one were extended via personalized email and phone calls to panelists based on their involvement and expertise in the PPC field in the United States. Eleven of fifteen panelists accepted the invitation, including five physicians, three advance practice nurses, a sonographer, chaplain and genetic counselor. The sample included five females and six males. The remaining invitees were unable to participate due to time constraints. All panelists have active clinical practices and work with families experiencing life-limiting fetal diagnoses. Nine of the eleven are published in the area of PPC. Figure 1 presents an overview of the Delphi Technique outcomes for this research study.

Appendix C (Continued)

Figure 1: Delphi Research: Stage One Progression




**Round One (R1)** was designed from the review of the literature and input from a small number of clinicians regarding the constructs related to perinatal palliative care. R1 included 44 items in 5 categories and the purpose of R1 was to elicit responses about whether each item should be kept in the instrument, eliminated or modified. Using a Likert Scale from 1-5, panelists were asked to rate each item with 1 indicating that the item was "not an important item" and 5 indicating the item is "essential" to include. Comment boxes to solicit input about dimensions of the construct of each item were included following each statement and at the close of each section.

Appendix C (Continued)

R1 was open for two weeks, and panelist participation was 100%. Specific comments from panelists provided thorough and robust feedback garnering additional insights into PPC. Results uncovered additional barriers experienced in various practice settings. Examples of open ended feedback from R1 are included in Table 1. Analysis of the data was completed, and a mean for each item was calculated using a five-point Likert scale which ranged from 1-5 points. Items with a mean less than or equal to 3.5 were eliminated or rewritten depending on written feedback. Changes to the items were based on panelists' comments, and several items in each section were added. These modifications were subsequently supported by the literature and/or other panelists.

Table 1: Examples of Open-ended Feedback on Round 1 from Panelists

| Panelist Open-ended feedback |
| --- |
| *"address roles and realities of clinical services – some patients will die, inability to cure does not preclude an ability to find fulfillment in providing care* |
| *"very important issues…from a place of good intention [physicians] think they should counsel strongly for termination, and only explore PPC if parents insist or ask about it. This is in counterdistinction to a balanced early presentation of options"* |
| *"These questions are important in terms of educational interventions"* |
| *"Clarifying ethical dimensions of PPC is important in establishing its legitimacy and breaking down barriers"* |
| *"Many of these [perceptions may be] characterized as myths, but since some people believe them, and they can be barriers to appropriate care, it is important to assess whether these misconceptions may be at play in a clinician's response"* |
| *"I think practitioners in general are uncomfortable talking about 'difficult' topics such as death or limitations of care"* |

Appendix C (Continued)

**Round Two (R2)** included 64 items in five categories and was circulated to the panelist asking for input on content and construct validity. The same Likert scale from R1 was utilized to measure whether an item was an essential item. Comments boxes appeared after each item, and specific written feedback was encouraged. Definitions for autonomy, beneficence/non-maleficence, and justice were provided and for the items measuring clinician perceptions, panelists were asked to choose the most appropriate ethical domain for each item. R2 was open for two weeks, and 100% of the panelists participated. Means for each item were calculated, and items with mean scores less than 3.5 were eliminated.

**Round 3 (R3)** included 65 items in four categories and proved to be the final round necessary to satisfy criteria for consensus. R3 was modified to represent the form and format in which the instrument would appear in its final draft. Table 2 provides examples. Likert scales were changed to a six-point scale for this round to improve variance. In the category "Perceptions of PPC," the scale measured the amount of agreement with each item with 1 representing "strongly agree" and 6 representing "strongly disagree." In the practice barrier category, a frequency scale was used with 6 meaning "always" and 1 meaning "never." Panelists were asked to complete R3 and email final comments on its usability and clarity. R3 was open for two weeks, and panelist participation was 91%. At the close of the Stage One, panelists were given a small honorarium for their participation.

Appendix C (Continued)

Table 2: Examples of Items on the Instrument Following Stage One Completion

| Select Perception Items |
| --- |
| Parents experiencing a life-limiting fetal diagnosis should be informed of the option for perinatal palliative care |
| Continuing a pregnancy to birth when the neonate has a lethal condition pus an undue emotional burden on families |
| Perinatal palliative care prolongs maternal suffering |
| Perinatal palliative care gives parents time to spend planning their infant's birth |
| Select Barrier Items |
| I can quickly consult maternal fetal medicine specialists to offer parents a fetal diagnosis, generally within several days |
| In the daily course of my practice, I have enough time to counsel families facing a potentially fatal prenatal diagnosis |
| Administrators at my facility support perinatal palliative care efforts |
| Offering PPC [to my patients] would cause me to feel pressured from colleagues |

Construct validity was fostered by having experts from the Delphi study brainstorm the domains of content. Then items were devised to measure each dimension, and the experts reviewed items to ensure that the instrument adequately captured the latent constructs of perceptions and barriers involved in PPC care. Content validity was evaluated by examination of the wording of items and the inclusion of items about autonomy, justice, beneficence/nonmaleficence, and self determination to adequately represent the a priori dimensions of PPC, including potential barriers that undermine care. Throughout the three rounds, items were reviewed for ambiguity and reworded as needed with input from panelists.

Appendix C (Continued)

## PPCPBS Instrument

Perinatal palliative care is viewed as a multidimensional construct which was measured by two subscale scores. Both subscales were reduced when items fell out in factor analysis using the Eigenvalue of 1 as a cut off. Using six-point Likert scales, the 23-item perceptions sub-scale derives a score ranging from 23 to 138 and the 22 item barriers sub-scale score ranges from 22 to 132. The instrument also measures two global comfort items on a 1-10 scale: personal comfort with PPC and comfort referring patients. Four open ended items ask clinicians to sum the total number of times: 1) they have dealt with families dealing with a PPC situation, 2) how many of those situations resulted in pregnancy termination, 3) how many resulted in continuation, and 4) how many times they referred families to PPC care. Demographic items include type of provider, gender, ethnicity, years in practice, annual deliveries, practice setting, and rural versus urban setting.

### Pilot Testing

The survey was completed by 264 clinicians: 26 physicians, 43 advanced practice nurses, 212 genetic counselors, 2 social workers, 2 sonographers, 3 chaplains, and 12 professionals active in perinatal medicine who identified themselves in the ‘other’ category. Physicians reported the most experience with families facing a terminal diagnosis with a reported number of cases ranging from 3 to 200 (M=41, SD=47.33 with the removal of two outliers who reported 500 and 1000 prior cases).

Geneticists reported a case history ranging from 0 to 500 (M=40, SD=70). Advanced practice nurses reported a case history of PPC ranging from 0 to 500 (M=28, SD=89). Factor analysis was done three times and the most parsimonious solution was derived from physicians and advanced practice nurses. The exclusion of the small subgroups (social workers, sonographers, chaplains, and unidentified professionals) improved the scale performance, and subsequent exclusion of geneticists further improved the scale performance. Healthcare providers, specifically nurses and physicians, most determine the course of the therapeutic relationship. They were felt to have more contact with the PPC families than the other groups and the improved scale performance validated that assumption.

**Exploratory Data Analyses and Instrument Assessment**

Eight items on the perceptions scale were reverse coded so that a higher sum score of perceptions corresponded with more positive perceptions. Seven items on the barriers scale were also reverse coded so that a higher sum represented more practice barriers. Exploratory factor analysis (EFA) using principal components analysis (PCA) with varimax rotation was performed on the perceptions scale for the initial 264 respondents. The Kaiser-Meyer-Olkin (KMO) value of 0.88 verified the sampling adequacy[13] indicating that factor analysis was appropriate. A significant Bartlett's test of sphericity $X^2$ (171) = 1495.75, ($p<0.01$) indicated the correlations between items were sufficiently large for exploratory factor analysis. Subsequent fit statistics validated the

adequacy of data for reduced sample analyses. In the perception subscale, an initial analysis and factors with eigenvalues over Kaiser's criterion of 1 demonstrated a 5 factor solution for 24 items (4 items failed to perform and fell out in the analysis) with an explained variance of 56.42% and an internal consistency reliability of 0.76. A subsequent analysis was done without the social workers and sonographers (n=2 each), the chaplains (n=3), and the "other" group (n=12). The rationale for exclusion was that groups with too few participants did not validly represent their professional group. Analysis without the 212 geneticists also improved the factor analysis results. These changes improved the tool validation, and the perceptions scale was reduced to 23 items with a 6 factor solution explaining 67% of the variance with a good internal consistency reliability of 0.77 using Cronbach's alpha. Not surprisingly, the most important factor that emerged from the perceptions scale and explained 32.64% of the variance included the 9 items pertaining to suffering. Table 3 shows the named factors, explained variance for each factor, and items which contributed to each factor. The same EFA procedures were used in the third and final analysis of the barriers scale and the sample was reduced to include only physicians and nurses. Again using the Kaiser's criterion of 1 for eigenvalues, the 22 item barriers scale had a 6 factor solution explaining 70.59% of the variance with a Cronbach's alpha reliability of 0.83 (2 items failed to perform and fell out in the analysis). Table 4 presents the 6 factor solution with the named factors and items that formed each component. The final instrument was then accepted to include 23 perception items, 22 barriers, and 16 demographic questions.

Appendix C (Continued)

Table 3: Perceptions Scale Factors and Explained Variance

| | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 | Factor 6 |
|---|---|---|---|---|---|---|
| Theme | Suffering | Plan & cope | Maternal Attachment | Spiritual | Ethics | Informed |
| Explained Variance | 32.64% | 10.69% | 7.0% | 6.04% | 5.65% | 4.64% |
| 1. | P19: prolongs mom suffering | P12: enhance trust | P2: bonding time | P24: equipped meet spiritual | P17: termination acceptable | P1: inform parents |
| 2. | P7: termination heals faster | P13: time to plan | P23: unwilling recommend PPC | P21: assess spiritual | P22: religion impacts advice | P6: too costly |
| 3. | P8: PPC emotional burden families | P20: gives voice | | | | |
| 4. | P15: PPC undue neonatal suffer. | P11: prepare for birth | | | | |
| 5. | P10: moms health paramount | P5: fetal assessments | | | | |
| 6. | P9: PPC $ burden society | P14: PPC less depression | | | | |
| 7. | P4: father stress | | | | | |
| 8. | P3: false hope | | | | | |
| 9. | P16: PPC grieve longer | | | | | |

Appendix C (Continued)

Table 4: Barriers Scale Factors and Explained Variance

| | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 | Factor 6 |
|---|---|---|---|---|---|---|
| Theme | Site Resources | Clinician Stressors | Time and Resources | Adverse Pressure | Societal Support | Termination Services Available |
| Explained Variance | 25.25% | 12.53% | 11.25% | 7.80% | 6.90% | 5.63% |
| 1. | B14: admin knows PPC | B8: provider distress | B10: quick consult MFM | B19: colleague pressure | B2: societal understanding | B7: termination allowed here |
| 2. | B23: organ. Support | B13: provider uncomfortable | B9: provider value | B18: admin pressure | B20: insurance coverage | |
| 3. | B21: access PPC | B16: not qualified | B12: time to counsel | | B3: societal support | |
| 4. | B22: meetings easy | B11: provider helplessness | | | | |
| 5. | B15: admin supports PPC | B17: time consuming | | | | |
| 6. | B6: team supports PPC | B1: education prepared | | | | |
| 7. | B5: lack team | | | | | |

Appendix C (Continued)

**Evaluating Perceptions and Barriers to PPC**

The PPCPBS instrument enables researchers to measure perceptions and barriers to recommending and providing palliative care in situations where the fetus has been shown to have a life-limiting condition. By summing each scale, the health provider's perceptions and anticipated barriers can be quantified for further analysis. The perceptions variable ranged from 83 to 128 (M=106.91, SD=10.94), and the barriers variable ranged from 33 to 88 (M=56.90, SD=12.22).

There were no significant differences between the perceptions of nurses and physicians. (t=.36, df=35, p=.72). This was also seen in Catlin's[14] study on neonatal palliative care. Both clinician groups reported a high score on the perceptions scale indicating similar concerns about the suffering experienced by the parents, their need for time to cope, and the need for clinician support of their ethical rights (nurses M=107.43, SD=9.57; physicians M=108.59, SD=13.33). Nor were there significant differences in the barriers scores (t= -1.59, df=58, p=.12) indicating similar experiences between nurses and physicians with barriers including site resources, clinician stressors in dealing with the complex issues involved with PPC, time restraints, adverse pressures and societal support for PPC (nurses M=58.42, SD=12.51; physicians M=53.38, SD=11.46).

## Recommendations

Experiences of perinatal loss stay in family histories indefinitely. Enhancing the quality of end-of-life care is a priority for patients, families and health care providers [15]. Perinatal palliative care is an option which seems to be well received by parents who are given a life-limiting prenatal diagnosis. Kuebelbeck[16] provides resources for professionals and lay people interested in a palliative care approach through a website www.perinatalhospice.org. Although limited information has been reported on this approach to care, it is hoped that a PPC alternative may offer parents support during their crisis and prevent some of the psychological sequelea that can be associated with termination [17]. The PPCPBS adds to the limited body of scientific inquiry regarding the perspective of healthcare providers who serve women experiencing unexpected fetal diagnoses. The instrument provides a venue in which health care workers can express their perspectives and identify concerns about how to support parents effectively through the PPC process.

Clinician experiences with couples continuing pregnancy may be limited and providers may be ill prepared to provide appropriate care [18]. A feeling of insecurity related to the lack of published data for reference can be addressed through research as a precursor to evidence-based practice. Examination of clinician perceptions and practice barriers to PPC services is indicated as is exploring a framework to guide clinical practice so providers are supported in their efforts to create a compassionate environment.

Research findings from use of the PPCPBS can identify barriers to PPC. These results will be useful to explore solutions to facilitate understanding and acceptance of a PPC model. Professional feedback may foster educational programs. In addition, an opportunity for multidisciplinary partnerships may be identified which can enhance the supportive environment provided to patients wishing to continue their pregnancy in light of a life-limiting fetal diagnosis. Strategic planning can identify resources within the healthcare sector which can provide grieving families with the varied support they need. The potential answers from research may recognize and support a PPC model of care and may allow nurses and physicians to engage in clinically relevant and cooperative approaches to care that will ultimately improve outcomes for women and their families.

## Summary

The PPCPBS instrument was designed with input from eleven experts with experience in dealing with families who received a life-limiting diagnosis for their infant during pregnancy. Eleven experts offered input through a three-round Delphi study on concepts and items resulting in the development and construct validation of an initial 65-item scale. Subsequent snowball sampling yielded a sample of 264 clinicians who completed the PPCPBS providing data used for validity and reliability assessment of the scale. Extremely small sub-groups of social workers, sonographers, and chaplains were

excluded after the initial assessment because the resulting factor analysis results demonstrated improved scale performance. Evaluation with and without a large group of geneticists led to their exclusion based upon the rationale that they had limited experience after diagnosis with care of PPC families, and their exclusion improved the scale performance. The final exploratory data analysis yielded a 23 item perception scale (alpha 0.77) with 6 components including suffering and time to plan, that explained 67% of the variation in physician and nurse perceptions about caring for families experiencing PPC. The 22 item barrier scale (alpha 0.83) had a 6 factor solution with components including site resources, clinician stressors, time and resources, adverse pressure, societal support, and termination services within the facility. The instrument provides a valid and reliable measure of provider's perspective and 1) provides the baseline health providers perspective and establishes the need for an interventions; 2) presents ideas for possible interventions; and 3) provides a metric for testing the resulting intervention. The scale adds to the limited body of scientific inquiry regarding the care for families facing the crisis of a fetus with a life-limiting condition as early as the first or second trimester.

Until there are instruments which speak specifically to the issues surrounding these types of uncommon situations, research will continue to be inadequate to offer health practitioners an evidence base from which to make informed and considered decisions. As prenatal diagnostics and genetic testing advance, the instrument will be useful for examining trends in clinician perspectives and perceived barriers related to

Appendix C (Continued)

PPC. Health care providers have a duty and privilege to study, promote, understand, and support processes that will bring healing and health to the families they serve.

Appendix C (Continued)

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Appendix D: Detailed Research Procedure Protocol

A total of 302 clinicians responded to the online survey. Of those, the 70% completed by physicians (n = 66) and APNs (n = 146) are described in this dissertation. SPSS 17 was used to analyze data. Descriptive statistics were used to calculate frequencies in demographic information such as race/ethnicity, gender, facility location, clinical setting, professional affiliation, number of cases with life-limiting fetal diagnoses in past five years, years of experience and personal perinatal loss.

**Exploratory Data Analysis**

Exploratory data analysis was done to evaluate parametric assumptions using methods recommended by Field (2009) and Mertler and Vannatta (2005). In this study, the 24 item perceptions scale performed better than in the 2010 pilot study with a reliability of 0.79 and the 22 item barriers scale also yielded a higher alpha reliability of 0.86. Sum scores were created for the perceptions and barriers scale and both variables were normally distributed with homogeneity of variance. The confidence, personal comfort, and referral comfort variables demonstrated mild skew and significant Kolmogorov-Smirnov tests so analyses were run and reported on both untransformed and transformed variables.

**Ha 1: PPC practice barriers differ between physicians and advance practice nurses**

Results suggest that practice barriers differ between physicians and nurses with nurses reporting more barriers. An independent t-test was used to compare the differences in physician and nurse reported practice barriers as measured by the subscale. Higher scores are indicative of better practice environments, with fewer barriers. There was a significant difference in the practice barriers described by physicians (M= 97.23, SD= 10.54) and nurses (M= 88.87, SD= 15.97); t(154) = 4.16, $p$ = .000. Further examination using Mann-Whitney U statistics for each item in the barriers subscale revealed significant differences in 11 of 22 barrier items. The latter calculations were done to explore discipline-specific issues. Significant test results were reported with $\alpha = .05$.

**Ha2: There are differences in perceptions as they pertain to perinatal palliative care between physician and advance practice nurses**

An independent sample t-test was used to measure differences in the 24 item perception scale. Responses from physicians and APNs reflected non-significant findings. Mann Whitney U was used to calculate the individual items because items were not normally distributed. Physicians and nurses differ in two perceptions. Physicians perceive that the option of ending a pregnancy in which the fetus has a life-limiting condition allows a family to heal faster ($U$ = 2.91, $z$ = -2.91, $p$ = .00, $r$ = -.20).

Physicians (mean rank = 88.83) rank this item significantly lower than nurses (mean rank = 114.49) indicating that physicians are more likely to see termination as an alternative that allows a woman to heal faster when compared to a woman who opts to continue the pregnancy. Physicians (mean rank = 91.87), more so than nurses (mean rank = 112.43), were also more likely to perceive that continuing the pregnancy to birth when the neonate has a fatal condition puts an undue emotional burden on families ($U$ = 2.35; $z$ = -2.35, $p$ = .02, $r$ = -.18).

**Ha3: PPC perceptions, PPC barriers, years in practice, PPC case history, referral comfort, personal comfort, and personal experience with perinatal loss explain clinician overall confidence in their ability to deliver PPC in their setting**

Exploratory data analysis was performed on the regression variables. Analysis was performed despite the non-normal distributions of the confidence, referral comfort, and personal comfort variables with plans to transform and rerun the regression. The assumption of multi-collinearity was not violated among the variables using the variable inflation factor (VIF) value parameters of values less than 10 and not substantially more than 1, indicating multi-collinearity is not a problem (Field, 2009). Mild heteroscedasticity was evident and may undermine generalizability.

Hierarchical multiple regression (MR) was used to test the hypothesis that clinician perceptions, barriers to PPC, years in clinical practice, referral comfort and personal comfort, and case history explain variation in confidence.

Perinatal loss and case history did not significantly improve prediction so they were deleted, and the MR was rerun. The best fitting model for predicting clinician confidence is a combination of the perceptions, barriers, years in practice, referral comfort and personal comfort.

Clinician perceptions, entered in the first step, accounted for a small yet significant proportion of explained variance $R^2$ of .039, $p$ = .012. The perception variable was entered first because in practice settings, perceptions about palliative care precede the intent to implement such care; barriers are encountered after implementation is attempted. The barriers variable entered next and was a powerful predictor with an $R^2$ change of .33. Years in clinical practice and referral comfort made modest, yet significant contributions, to the model. Personal comfort with PPC, entered 5$^{th}$, made a significant contribution with an $R^2$ change of .15. A significant regression equation was found (F(5, 157) = 42.037, $p$ < .001) with an overall $R^2$ of .559.

Data transformations to three variables that were not normally distributed (confidence, personal comfort, and referral comfort) and missing data management using nearby points in cases with less than 20% missing values did not make major differences in the model outcomes. The resulting and final hierarchical multiple regression for the overall model was $R^2$ of.56, F (5, 157) = 42.04, p < .000.

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Appendix E: IRB Approval

The University of Texas at Tyler

Institutional Review Board

March 28, 2011

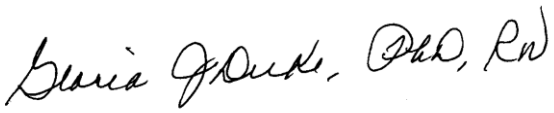
Dear Ms. Wool:

Your request to conduct the study entitled: *Perinatal Palliative Care: Assessment Of Practice Barriers And Clinician Perspectives And Confidence – Part 2* IRB #Sp2011-50, has been approved by The University of Texas at Tyler Institutional Review Board as an exempt study. This approval includes a waiver of written informed consent. **Please acknowledge your understanding of the following through return of this email to the IRB Chair within one week after receipt of this approval letter**:

- This approval is for one year, as of the date of the approval letter
- Request for Continuing Review must be completed for projects extending past one year
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and please do not hesitate to contact any member of the IRB or me if we can be of any assistance.

Sincerely,



Biographical Sketch

| NAME<br>Charlotte Wool | POSITION TITLE<br>Doctoral Candidate, University of Texas at Tyler<br>Assistant Professor of Nursing, York College of Pennsylvania |
|---|---|
| eRA COMMONS USER NAME (credential, e.g., agency login)<br>cwool | |

EDUCATION/TRAINING

| INSTITUTION AND LOCATION | DEGREE *(if applicable)* | MM/YY | FIELD OF STUDY |
|---|---|---|---|
| Bloomsburg University | BSN | 12/87 | Nursing |
| University of Phoenix | MSN | 06/04 | Nursing |
| University of Texas at Tyler | PhD | 12/11 | Nursing |

*A. Personal Statement*

The goal of the proposed research is to investigate the clinician perspectives and practice barriers to perinatal palliative care (PPC), a formal model of care delivery which provides supportive services to families who wish to continue their pregnancy after being given a poor prenatal diagnosis. Specifically, I plan to measure clinician perspectives, confidence, referral practices, and perceived barriers to PPC service implementation. I have the expertise, leadership and motivation necessary to successfully carry out the proposed work. I have a broad background in perinatal services, with specific expertise working with clinicians and experience with bereaved families. As a doctoral student at University of Texas at Tyler, I laid the groundwork for the proposed research by leading experts across the nation in a Delphi study to development an instrument to measure clinician perceptions and reported practice barriers to PPC. The instrument was then successfully piloted with several hundred respondents. As a result of the previous experiences, I am aware of the importance of frequent communication among project members and of constructing a realistic research plan, timeline and budget. In summary, I have a demonstrated record of accomplished and productive research projects in and area

of high relevance for clinicians who work with bereaved families and my expertise and experience have prepared me to lead the proposed project.

*B. Positions and Honors*

**Positions and Employment**

| | |
|---|---|
| 2011 - | Assistant Professor of Nursing, York College of Pennsylvania |
| 2001-2011 | Adjunct Professor of Nursing, Messiah College, PA |
| 2004-2011 | Perinatal Clinical Nurse Specialist, Holy Spirit Hospital, PA |
| 1990-2004 | Maternal Child Education Coordinator, Holy Spirit Hospital, PA |

**Other Experience and Professional Memberships**

| | |
|---|---|
| 2011- | Pennsylvania Section Chair, Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) |
| 2010- | Editorial Advisory Board, Health for Moms and Babies Magazine |
| 2007- | Board of Advisors, Pennsylvania AWHONN |
| 2005- | Member, Sigma Theta Tau |

**Honors**

| | |
|---|---|
| 2007 | Nightingale Award Nominee |
| 2010 | Outstanding Chapter Leader, AWHONN |

**C. Selected Peer-reviewed Publications**

Wool, C. Systematic review of the literature: Parental outcomes after diagnosis of a fetal anomaly. Adv Neonatal Care 11(3): 182-192. PMID: 21730912 [PubMed - in process]

Wool, C & Northam, S. The Perinatal Palliative Care Perceptions and Barriers Scale Instrument©: Development and Validation. Adv Neonatal Care, In Press

Merritt TA, Catlin A, Wool C, Peverini R, Goldstein M, & Oshiro B. Trisomy 18 and 13 infants: Treatment and management decisions. Neoreviews, In Press

*D. Research Support*

Completed Research Support

| | | |
|---|---|---|
| STT-HPNF | Wool (PI) | 08/01/2010 – 07/31/2011 |